Evaluation of a mutual support group for family carers of patients with schizophrenia

Chien, Wai-Tong

UNIVERSITY OF LONDON

KING'S COLLEGE LONDON

THE FLORENCE NIGHTINGALE SCHOOL OF

NURSING & MIDWIFERY

EVALUATION OF A MUTUAL SUPPORT GROUP FOR FAMILY CARERS OF PATIENTS WITH SCHIZOPHRENIA

By

WAI TONG CHIEN

THESIS FOR DOCTOR OF PHILOSOPHY

Submitted in October 2006

SUPERVISORS:

PROFESSOR IAN NORMAN

PROFESSOR DAVID R. THOMPSON

ABSTRACT

Schizophrenia is a disruptive and distressing illness for both patients and their families who are inadequately prepared for caregiving and thus find the responsibility a heavy burden. Studies demonstrate that family-centred intervention in cases of schizophrenia is important and effective. However, little is known about the effects of such interventions for family members, particularly those living in non-Western countries.

This randomised controlled trial examined the effectiveness of a 12-session mutual support group conducted over six-months for Chinese family caregivers of a relative with schizophrenia, compared with the experience of those family caregivers receiving routine outpatient services in Hong Kong. Seventy-six family caregivers from two psychiatric outpatient clinics were selected randomly from the patient lists and allocated randomly to a mutual support group or to a standard care group (i.e. 38 families per group). A variety of psychosocial outcomes for the families and patients were measured during their recruitment, and at one week, 6 months and 12 months following the intervention. Semi-structured interviews and audio-taped group session data were recorded to identify the therapeutic mechanisms of the support group.

The statistical results indicated that the mutual support group experienced significantly greater improvements with respect to the family burden, functioning and social support, and the functioning and re-hospitalisation of the patients, when compared with the control group over a 12-month follow-up period. The support group also reported a greater reduction in their need for family services during the follow-up than did the control group. In addition, a majority of the support group participants also indicated clinically significant changes in these outcomes when followed up 12 months after the intervention.

The analysis of the interview and group session data elicited four therapeutic mechanisms of the mutual support group. These included: reconstructing a new positive self-image in relation to caregiving; establishing and focusing on clear, realistic common goals and tasks; the psychological empowerment of carers through the acquisition of knowledge and

skills for caregiving; and extending the social support networks both within and outside the group.

The findings contribute to existing knowledge of the effects of mutual support groups on non-Western populations, and also to our understanding of the mechanisms of action of such groups. The study shows that a mutual support group can provide benefits for Chinese families of people with schizophrenia that go beyond those provided by routine family support. The four therapeutic mechanisms of the support group provide insights that might be drawn upon by health professionals when designing family group interventions.

TABLE OF CONTENTS

LISTS OF TABLES AND FIGURES

Page

List of Tables

List of Figures

APPENDICES

GLOSSARY

BPRS	Brief Psychiatric Rating Scale
CPNS	Community psychiatric nursing service
FAD	Family Assessment Device
FBIS	Family Burden Interview Schedule
FSSI	Family Support Services Index
OPD	Psychiatric outpatient department/ clinic
RCI	Reliable Change Index
RCT	Randomised controlled trial
SLOF	Specific Level of Functioning scale
SSQ6	Six-item version of the Social Support Questionnaire

ACKNOWLEDGEMENTS

My experience in this PhD study enriched my knowledge and skills in family group work for Chinese people with schizophrenia and enhancing mutual support as health promotion strategy for these family carers. To every participant (families) in this study, I would like to give my sincere thanks for their co-operation and time over the 18-month study period. Without their participation, this study would not be completed and evaluation of the study outcomes could not be done.

I would like to express my deep gratitude to my supervisors, Professor Ian Norman and Professor David R. Thompson for their continuous support, encouragement, inspiration, and advice. Their expertise in this area of research and mental health promotion have guided and facilitated my design, implementation and writing up the thesis throughout the past four years.

Special thanks is also given to the staff in the outpatient clinics under this study and my colleagues in mental health research team for their support and assistance in the access of potential study subjects, arrangement of venues and equipment for the support group sessions, and data management.

For statistical data analysis, I would like to express my thanks to Prof. Bill Goggins who is a consulting statistician at my university in Hong Kong, for his valuable advice on statistics used in this study.

I give wholehearted thanks also to my family, particularly my wife Isabella, and to close friends for their constant encouragement and support to complete the PhD study and write up this thesis.

PUBLICATIONS GENERATED FROM THE PHD STUDY

1. Chien, W. T., Norman, I. & Thompson, D. R. (2006) Perceived benefits and difficulties experienced in a mutual support group for family carers of people with schizophrenia. **Qualitative Health Research**, 16(7) September, pp.962-981.

2. Chien, W.T. & Norman, I. (2004) The validity and reliability of a Chinese version of the Family Burden Interview Schedule. **Nursing Research**, 53(5) September-October, pp.314-322.

3. Chien, W.T., Norman, I. & Thompson, D.R. (2004) A randomized controlled trial of a mutual support group for family caregivers of patients with schizophrenia. **International Journal of Nursing Studies**, 41(6), pp.637-649.

4. Chien, W.T. & Norman, I. (2003) Educational needs of families caring for Chinese patients with schizophrenia. **Journal of Advanced Nursing**, 44(5), pp.490-498.

CHAPTER 1 BACKGROUND AND ORGANISATION OF THE THESIS

1.1 INTRODUCTION

This background chapter provides a brief overview of schizophrenia, problems faced by people with this illness and different approaches to their treatment and care. A brief description of psychosocial interventions, in particular family interventions, in providing community mental health care for patients with schizophrenia sets the scene for the more detailed literature review in Chapter 2, which describes the impact of schizophrenia on family carers and the development of family intervention, while Chapter 3, discusses the potential of the mutual support group as the mode of family intervention used in this study. The study objectives are presented in Section 1.3 and finally the organisation of this PhD thesis is described in Section 1.4.

1.2 SCHIZOPHRENIA AND ITS TREATMENT IN THE COMMUNITY

Among the major psychiatric disorders, schizophrenia is the most disabling and devastating and is characterised by profound disruption in cognition and emotion, often resulting in loss of self-care and social functioning in affected individuals. People with schizophrenia therefore require long-term care and the illness consumes a disproportionate share of hospital and community mental health services. Even though profound changes have occurred in the conceptualisation and management of schizophrenia in the past few decades, its diagnosis remains clinically focused on its symptoms (Canavan, 2000). The array of symptoms, while wide ranging, frequently includes psychotic manifestations such as hallucinations - hearing internal voices or experiencing other sensations not connected to an obvious source, and delusions - assigning unusual significance or meaning to normal events or holding fixed false personal beliefs. According to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (American Psychiatric Association, 1994), no single symptom is definitive for diagnosis; rather, the diagnosis encompasses a pattern of signs and symptoms, in conjunction with impaired occupational or social functioning. Onset of illness occurs generally during young adulthood (mid-20s for men, late-20s for women), although earlier and later onset does occur. Onset may be abrupt or gradual, but most people experience some early signs, such as increasing social withdrawal, a marked loss of interest, unusual behaviour, or decrease or loss of everyday functions prior to the

onset of active positive symptoms (Lefley, 1996). These are often the first set of behaviours to cause their family members and friends concern.

The number of people with schizophrenia globally is estimated at about 29 million, of whom 20 million live in developing or less developed countries (Barbato, 1998). Cross-national epidemiological studies show that the annual incidence of schizophrenia is between 0.07 and 0.14 new cases per 1,000, the point prevalence is between 2.5 and 5.3 per 1,000, and the lifetime risk of developing the illness is between 7 and 9 per 1,000, or approaching 1 in 100 of the population (Jablensky et al., 1992). Similarly, in Hong Kong, over 100,000 people (about 1.7% of the total population) are estimated to suffer from schizophrenia and other psychotic disorders (Hospital Authority Hong Kong, 2003). As reported by Warner and De Girolamo (1995), about two-thirds of people with schizophrenia are estimated to suffer over a three-year or longer period: about 20% showing unremitting symptoms and increasing disability and 35% showing a mixed pattern with varying degrees of remission and exacerbations of different length. In fact, in Hong Kong and worldwide, schizophrenia remains the major diagnostic category for individuals requiring periodic psychiatric hospitalisation and is amongst the top 10 causes of long-term disability (Barbato, 1998).

Mason et al.'s (1996) study in Nottingham (UK) over a 13-year follow-up period, found that over 82% of first episode cases relapsed and about 75% had at least one readmission to inpatient care. Relapse and subsequent readmission, particularly in the first five years of illness, can therefore be expected to occur in the majority of patients with schizophrenia; perhaps half of them will develop the chronic syndrome, if they are not properly treated at the earliest opportunity. Persons with schizophrenia are typically high-cost users of community and inpatient health care services (Weiden & Olfson, 1995). In the USA, schizophrenia and other psychotic illnesses impose over a $70-billion burden on the economy per annum (United States Department of Health & Human Services, 1999), and in the UK these illnesses imposed over £4 billion in 2001 (National Collaborating Centre for Mental Health, 2002). This includes the direct costs of professional health care for individuals in hospital and community services and the indirect costs related to the social welfare services as well as loss in productivity and morbidity. Similarly, in Hong Kong, the costs of schizophrenia account for an

estimated over 2% of all economic and social expenses per annum (Census & Statistics Department, Hong Kong, 2003; US Institute of Medicine, 2001).

Antipsychotic medications have been the mainstay for managing schizophrenia since the discovery of chlorpromazine in the 1950s. Recently, more effective and better tolerated atypical neuroleptics, such as clozapine and risperidone, have been found to reduce the unwanted effects such as acute extra-pyramidal symptoms, which are one of the major reasons for medication refusal or non-compliance (Weiden et al., 1998). Rapid advances in biological psychiatry have also resulted in dramatic improvements in the treatment of schizophrenia. It was believed that symptoms of patients with schizophrenia or other serious mental illnesses could be effectively managed by antipsychotics and other psychotropic medications and, therefore, would allow patients to be easily managed in community-based settings, and also by their family members at home (MacCarthy et al., 1989). However, this optimism is not justified in many cases. Given the high risk of relapse following an acute episode of schizophrenia, antipsychotic drugs may be continued for up to two years after discharge or a relapse. Advice about drug treatments for both patients and their family carers is essential for maintaining recovery. However, a review of clinical trials since 1990 by Dickerson (2000) found that over 70% of patients with schizophrenia are non-compliant with medication and up to 50% have persistent psychotic symptoms even when adhering to pharmacological treatment.

Although psychopharmacological treatment is essential for achieving better physical and cognitive functioning in schizophrenia, a narrowly focused biological model has been shown to be inadequate if patients' potential is to be maximised (Wiedemann et al., 2001). Sufficient knowledge about the illness and its pharmacological treatment and other management should be provided to patients and their carers in order to minimise their reluctance to accept medical treatment. Moreover, in order to help improve the experience and outcomes of care for people with schizophrenia, it is recommended that mental health and social care for these patients should, therefore, be comprehensive and address physical and medical, psychosocial, occupational, and cultural issues (National Collaborating Centre for Mental Health, 2002).

Since the 1980s, in Western countries, the deinstitutionalisation movement in psychiatry has shifted the focus of patient care from long-term in-hospital treatment to less

stigmatised community management of mental illness, in order to alleviate custodial warehousing and traditional care in psychiatric hospitals. In the 1990s, the number of people cared for by inpatient facilities in the USA and the UK was reduced substantially and the downward trend continues (US Department of Health and Human Services, 1999; National Collaborating Centre for Mental Health, 2002). Similarly, this trend has been established in Hong Kong since the late 1990s and mentally ill patients have increasingly been discharged early to less-restrictive community-based facilities, such as half-way houses, hostels and their own homes.

The effects of schizophrenia on a person's life experience and opportunities are considerable; patients and family carers need help and support to deal with their future, and to cope with the changes the illness brings to their lives. Repeated education in medication compliance and symptom-focused programmes may not take into consideration the life circumstances and immediate living environment that are central to the patient's illness experience (Kapur & Remington, 2001). Although rapidly developed pharmacology is effective for treating acute symptoms and reducing factors influencing vulnerability to relapses, it does not alleviate residual cognitive and social deficits, such as impaired social relationships (Kane & Marder, 1993). Nevertheless, research on community mental health services use in the US (Dixon et al., 1999) found that less than one-third of patients in the community indicated that they and their families had received adequate information, satisfactory psychological support, or practical advice about management of their illness from health professionals and services. Kane and McGlashan (1995) suggest that in order to address the heterogeneity of schizophrenia, a system of care is required, which includes psychosocial interventions embedded in pharmacological and routine care, that is, a bio-psychosocial paradigm that attempts to be all-encompassing. Health professionals should work in partnership with patients and their carers, offering help, treatment and care in an atmosphere of hope and optimism (National Collaborating Centre for Mental Health, 2002). It is becoming increasingly important for mental health nurses and other mental health professionals to work with patients and family carers to provide appropriate and effective family services for education, support and psychosocial care (Brooker, 2001).

In Hong Kong, 'routine' care for patients with schizophrenia is provided by the psychiatric outpatient clinics, mainly consisting of monthly medical consultations with a psychiatrist who provides the patients and their families with a prescription of mainly neuroleptics, information about the illness, a treatment plan and information on the effects of the prescribed medications. Other services, including: (1) advice on daily patient care, possible referral to other mental health services, and education seminars on schizophrenia care organized by psychiatric nurses; (2) individual family counselling by clinical psychologists; and (3) advice on financial aid and social welfare services by medical social workers, are optional and not provided on a regular basis. The dominant medical and neurobiological approaches of care for patients with schizophrenia in Hong Kong as well as many Western and Asian countries, do not address the potentially overwhelming psychological, interpersonal and social obstacles faced by those with such severe mental illness (Bellack, & Mueser, 1993; Pearson & Ning, 1997; Canavan, 2000). Moreover, in addition to the essential pharmacological treatment, regular and specifically designed psychological and social interventions are often limited and not integrated into current mental health services.

Thus the routine care and services described do not adequately reflect the body of evidence, which has emerged over the past two decades, demonstrating that community-based psychosocial interventions can improve the long-term outcomes of patients with schizophrenia and other severe mental illnesses. An overview of these psychosocial interventions for patients with schizophrenia described in Section 1.2.1, indicates that patients with schizophrenia can be better managed within the community, and so sets the scene for the study described in this thesis.

1.2.1 Psychosocial interventions for people with schizophrenia

Until the 1980s, there was little evidence that psychosocial treatments or interventions could improve the course of schizophrenia. But over the past two decades this has changed. There is now more evidence that psychosocial interventions are effective in relieving symptoms of patients with schizophrenia and in improving their functioning. Adams et al. (1998) in their systematic review of studies for schizophrenia suggested that psychosocial interventions are considered to be an indispensable part of the treatment options available for patients with schizophrenia, in an effort to promote recovery and

community care. Three major categories of psychosocial intervention in the community-based treatment of patients with schizophrenia have frequently been used with evidence of efficacy on relapse prevention and symptom control. These include: social skills and other coping skills training programmes; case management or assertive community treatment; and cognitive-behavioural therapy (Mueser, Bond & Drak, 2001). Even though the process of these interventions is not always described clearly, each type of intervention model has an individual set of goals, objectives and treatment agenda and all have been found effective in improving different aspects of functioning of patients with schizophrenia. However, it should be noted that there are difficulties in implementing these interventions in everyday clinical practice in community care settings. First, staff may not be adequately trained to implement the intervention. Second, since these interventions need to be implemented for between 9-12 months, there may be insufficient resource to deliver and evaluate them adequately (Brooker, 2001). Finally, there may be inadequate recognition and support from service managers in terms of service strategy collaboration, resources and time to embed these interventions into existing mental health services (Fadden, 1998).

Of these psychosocial interventions for schizophrenia, social skills training has the longest history, having been used to help people with schizophrenia learn to cope with interpersonal relationships and develop communication and community living skills since the 1960s. Reviews of more than 70 studies of social skills training for patients with schizophrenia (Dilk & Bond, 1996; Fenton, 2000) concluded that skills training produces significant improvements in living skills and interpersonal relationships, and increasing social adjustment of patients. However, its effectiveness in reducing symptoms and relapse, improvement on community functioning and other complex social skills such as assertiveness and communication skills, are less pronounced (Penn & Mueser, 1996).

The assertive community treatment (ACT) model of case management has been found to be an effective intervention to improve treatment outcomes of patients with schizophrenia and other severe mental illnesses with poor treatment compliance. This has been shown to be particularly effective for those who: make particularly high use of inpatient services; have a history of poor engagement with services leading to frequent relapse and/or social breakdown (for example, as manifested by homelessness, non-

compliance with treatment, social withdrawal, loss of contact with routine services, or seriously inadequate accommodation); or need urgent or immediate access to assistance or support in crises (Craig et al., 2004; Warner & De Girolamo, 1995). However studies indicated that ACT does not have any consistent positive effect on social adjustment and functioning (Herdelin & Scott, 1999).

Over the last decade in the UK, cognitive behavioural therapy (CBT) has also been used to treat schizophrenia. During this period it has emerged as a promising treatment modality for individuals with schizophrenia whose psychotic symptoms such as delusions and hallucinations are not controlled by medication (Haddock et al., 1998). Although some studies have found CBT to have positive benefits in terms of reduction of positive symptoms and recovery time, it has not yet shown proven benefits for patients in community care settings (Sensky et al., 2000; Thornicroft & Susser, 2001). In addition, CBT requires experienced and skilled practitioners, the essential and effective components in the intervention to be clearly defined and for the practical demands on patients in terms of time for regular sessions and high level of concentration and insight to be managed. Therefore, as Repper (1999) has pointed out, these requirements would exclude a high proportion of more disabled patients and limit its widespread dissemination into routine practice.

Over the past few years in the US and UK there has been a great deal of interest in early intervention for first-episode schizophrenia and other psychotic disorders, generating enthusiasm and hope in both clinicians and the public. An early intervention programme seeks to reduce delays in providing treatment to people of first-episode psychosis and supports the importance of early detection of prodromal signs of relapse with a view to preventing relapse and re-hospitalisation, or promoting better treatment outcomes (Malla & Norman, 2002). However, it is not easy to identify patients with schizophrenia and other psychoses in the early stages of illness as patients and families may often fail to recognise the illness and its symptoms. Also families may be reluctant to report early symptoms of a family member through fear or because of the stigma of mental illness. Failure to recognise or report early symptoms means that assessment and treatment may be delayed, which in turn may result in more severe symptoms, acute hospitalisation, longer treatment period, and increased distress and suffering of patients and their families.

1.2.2 Family intervention as an alternative way of community care for schizophrenia

As those interventions described in Section 1.2.1 have been found to improve only narrowly focused aspects of patient functioning or to be effective with only specific patient subgroups, more effective methods of psychosocial interventions are essential to improve treatment outcomes of patients with schizophrenia. In addition, there has been increased recognition that family members are the main carers for patients with schizophrenia in the community and thus are central to the success of community care for these patients. There has been an increased interest in developing and testing different models of family intervention for schizophrenia over the past two decades. Recent reviews (Barbato & D'Avanzo, 2000; Pharoah et al., 2001) of more than 30 clinical trials of different modes of intervention from 1980 to 2000 such as family behavioural management and psychoeducation programmes, revealed that family intervention, as an adjunct to drug treatment and routine care, can enhance family members' knowledge about the illness, reduce relapse rates, and improve medication compliance.

The National Institute for Clinical Excellence (NICE) in its clinical guidelines to the National Health Services in England and Wales (National Collaborating Centre for Mental Health, 2002) also recommends that pharmacological treatment for people with schizophrenia should be better integrated with other psychological, social and educational interventions at the earliest opportunity. Working with families appears to be one of the most effective ways of delivering community-based intervention to these patients.

Most outcome studies of family interventions have used different modes of treatment that cannot be easily compared. The protocol and procedure of family intervention, as well as the therapeutic elements within the family programmes, are not clearly described and, thus, provide limited guidelines which are not sufficiently detailed to replicate the intervention and shape effective clinical practice. Budd and Hughes (1997) suggested that future studies should address the therapeutic process in addition to outcome and identify which aspects of the interventions are effective for the families who participate in the programme. Thus, emphasis in the present study is on the therapeutic mechanisms by which a mutual support group might produce positive effects for Chinese caregivers. The findings of the study reported in this thesis add to the knowledge base of

interventions for families of patients with schizophrenia. They provide new insights for mental health professionals into the selection and design of appropriate interventions for these families, for effective community-based care of schizophrenia.

1.3 OBJECTIVES OF THE STUDY

The objectives of the study reported in this thesis were to:

1. Estimate and compare the immediate impact and substantive effect of a mutual support family group plus usual psychiatric outpatient service (the intervention) with usual family support service alone (the comparison) for a sample of Chinese families caring for a relative with schizophrenia managed within two psychiatric outpatient departments in Hong Kong on:
   a) A primary outcome: family burden of care;
   b) Secondary family outcomes: family functioning, perceived social support, family conflicts and utilisation of available family support services.
2. Estimate and compare the impact of the two interventions on the following patient outcomes: level of functioning, symptom severity and length of re-hospitalisation over the 12-month follow-up period.
3. Identify the therapeutic mechanisms of the mutual support group model of family intervention for patients with schizophrenia.

1.4 ORGANISATION OF THE THESIS

1.4.1 Literature review

Chapter 2 describes the impact of schizophrenia on family carers and the development of family interventions. It examines the theoretical basis and relative effectiveness of different types of family intervention for people with schizophrenia and introduces the mutual support group as a potentially effective intervention to improve care for patients suffering from schizophrenia living in the community.

Chapter 3 describes the major theoretical perspectives applied to mutual support groups for family caregivers. It also examines the evidence supporting the effectiveness of mutual support groups for families of patients with schizophrenia and other severe mental illnesses, and the active ingredients of the support groups. The limitations in our knowledge of the effects of the mutual support group and its therapeutic mechanisms are

discussed. Lastly, this chapter provides a rationale for the evaluation design used in the study described in this thesis.

1.4.2 Development of the mutual support group intervention

Chapter 4 describes the development of the mutual support group intervention used in this study. A pilot study of the group intervention conducted from June to November 2002 to test the support group intervention protocol and procedure, its feasibility, and the impact on 24 family carers immediately after the group intervention (when compared to a control group of 24 family carers) is also presented, followed by recommendations for improvements in the group intervention which was implemented in the main study reported in this thesis.

1.4.3 Method for evaluation

Chapter 5 reports pilot testing of the research instruments used in the main study and steps taken to ensure satisfactory reliability and validity of the instruments.

Chapter 6 sets out the methodology for the implementation of the six-month mutual support group intervention for the family carers of patients with schizophrenia and evaluation of its effectiveness on a variety of family and patient outcomes over a one-year follow-up period. It also describes the method for analysing data from interviews with participants and the audio-taped mutual support group sessions in order to: explore perceived benefits and problems of the group participation as perceived by participants; examine the development of the mutual support group, and individual and group level changes among participants over the course of treatment; and identify the therapeutic elements of the mutual support group.

1.4.4 Results and discussion

Findings which address the first two objectives of the study (see Section 1.3) are presented in Chapter 7, which describes the data collected by the randomised controlled trial to evaluate the effectiveness of the mutual support group intervention. Findings, which addressed the study objectives three, are presented in Chapter 8, which describes the results of the semi-structured interviews with the group participants and the audio-taped data of the group sessions.

Chapter 9 draws together the findings from the outcome and process evaluation as a whole and considers them in the light of previous research, particularly those studies described in Chapters 2 and 3. Chapter 10 provides a methodological critique of the main study. The contributions of this study to knowledge and implications for clinical practice are described in Chapter 11; the wider implications for mental health care policies and research are also discussed. The conclusions of the study are presented at the end of Chapter 11.

CHAPTER 2 THE IMPACT OF SCHIZOPHRENIA ON FAMILY CARERS AND THE CONTRIBUTION OF FAMILY INTERVENTIONS TO CARE AND TREATMENT

2.1 INTRODUCTION

The previous chapter has described how schizophrenia is a major mental illness globally with high risk of relapse following an acute episode of illness, requiring both pharmacological and psychosocial treatment delivered by community and inpatient health care services. It demonstrated that among psychosocial interventions, family intervention has been found to be effective. This chapter describes the impact of schizophrenia on family carers and how families cope with the illness (Section 2.2). The development of family intervention as one of the approaches of psychosocial intervention commonly used for patients with schizophrenia is described in Section 2.3. Section 2.4 presents the different modes of family intervention frequently used in the past 20 years and their theoretical basis in.

A review was undertaken to assess the relative effectiveness of different modes of family intervention for family carers of people suffering from schizophrenia and is presented in Section 2.5. An initial literature search up to the start of 2002 was undertaken to fill in gaps in the knowledge about family intervention for schizophrenia and, thus, provide a rationale for this PhD study that would make an original contribution to add to the existing knowledge. Further studies continued to be added to the review throughout the PhD study period, and thereafter up until December 2005. An appropriate search strategy using a wide variety of publication databases is crucial to the inclusion of comprehensive and relevant literature and thus the success of any review (Cullum, 1994). A broad range of electronic bibliographic databases in medicine, health care, nursing, psychology and social sciences were searched from 1985 – 2005. These databases were: American College of Physicians (ACP) Journal Club, CINAHL, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Embase, Medline, NHS Database of Abstracts of Reviews of Effects (DARE), Ovid, PsycINFO, and Social Sciences Citation Index. My literature search covered 1985 onwards, mainly because from the mid 1980s there were an increasing number of research studies and

controlled trials of family interventions and the findings of these studies have established a more sound evidence base on the effect of family environment and family-focused intervention for schizophrenia (Pharoah et al., 2001). Early citations were followed up and the searches were restricted to English language. The search strategy is described in detail in Appendix I.

Other sections of the chapter cover: the cultural and practical issues that are pertinent to the use of a multiple-family group intervention in a Chinese population (Section 2.6); and the emergence of mutual support group intervention for family carers of people suffering from severe and enduring mental illnesses during the past 20 years (Section 2.7). The chapter concludes by providing a rationale for this PhD thesis, which reports the implementation and evaluation of a mutual support group intervention for helping family carers of people with schizophrenia.

2.2 THE IMPACT OF SCHIZOPHRENIA ON FAMILY CARERS

Despite the rapid development in pharmacological and psychosocial treatment of schizophrenia, the dissemination of psychosocial interventions as usual practice within mental health services has been slow and patchy (Penn & Mueser, 1996). Specialised care and new early intervention services may be a means of engaging patients in community mental health services and reducing patients' re-hospitalisations; however, limited evidence exists because of wide variations in implementation with little guidance or inadequate funding from the health authorities towards early detection, home treatment, and services to prevent relapse (Craig et al., 2004). Many newly invented neuroleptic drugs can give patients partial protection against environmental stress to the patients, but they need to be supplemented with a therapeutic social environment, especially a healthy and supportive family. However, the shortcomings of community care have produced many negative consequences for the families of the mentally ill, who are often coerced into the service to compensate for the deficiencies of the community care system (Saunders, 1999).

Families, particularly those family members who live with their relative with schizophrenia, often face daily stressors including the patient's unpredictable and bizarre behaviour, external stressors of social stigma and isolation, emotional frustration such as

guilt and loneliness, and family conflicts which arise during the caring process (Leff, 1994). Studies have shown that family caregivers may report psychological distress, social and family disharmony, and practical problems in living with and taking care of the patient at home. Similarly Brooker (1990) and Canive et al. (1996) describe family carers as suffering from depression, anxiety, grief and somatic complaints, as well as disruption to their social and leisure activities and domestic routine, and reduction in household income. Therefore, caregiving for family members with schizophrenia is extremely stressful and burdensome, with negative consequences for the social and psychological health of caregivers, indicating the importance of health professionals providing family oriented mental health care (Loukissa, 1995).

The impact of caring for persons with schizophrenia and other severe mental illnesses is often described as burdensome and includes the physical, psychological or emotional, social, and financial problems experienced by family caregivers representing both subjective and objective aspects of the impact of care (Marsh, 1998). Research from the mid 1950s (Clausen & Yarrow, 1955), has indicated that the caregivers' psychological well-being can be seriously impaired; and subsequently family burden has become an increasingly important area of concern in studies on family caregiving.

2.2.1 Concept of family burden

Family or caregiver burden has been frequently used to refer to the totality of the experience of caring for an ill relative, including effects on the physical, psychological and socio-economic well being, as well as the capacity to cope with and adjust to that circumstance (Rose, Mallinson & Walton-Moss, 2002). From the 1970s to the 1980s, the adverse consequences of mental illnesses for family caregivers, known as family burden, have been studied to either determine the feasibility of discharging a patient into their community or to refine the concept of caregiving and its underlying structure and content (Schene, Tessler & Gamache, 1994). Since then, the concept of family burden has become universal, with numerous studies in the West and relatively fewer works from the Eastern world such as Asia and Australia (Ustun, 1999); and there have been at least 17 reviews of caregiving experience and burden for patients with severe mental illness from 1987 to 2002 (Ohaeri, 2003). Studies have indicated consistently that there may be

severe distress and burden upon the whole family in living with a relative with schizophrenia, particularly for the primary caregiver; it is because family members' needs are often superseded by those of the patient (Maurin & Boyd, 1990). The US administration proposed a US$6 billion five-year project to address the long-term care needs of patients with chronic mental illness and their families (Arno, Levine & Memmott, 1999), whereas in the UK the National Service Framework for Mental Health reported by the Department of Health (1999) recommended that caregivers' health needs such as psychological distress and caregiving burden should be taken into account when providing community-based care to patients with severe mental illness in the UK (Treasure et al., 2001).

In recent years, the concept of burden has been broadened into a multidimensional construct (Woods, Haberman & Packard, 1993). Using rating scales, the concept of family burden is quantified as objective burden, which refers to the observable consequences of caregiving on family life such as financial loss, impairment of work efficiency, and disruption of family routines; and subjective burden, which refers to the psychological reactions and attitudes towards caregiving such as attitudes to the patient, emotional climate at home and subjective feeling of difficulty coping with the illness, when these problems are attributable to the illness (Schene, 1990). As the concept of caregiver burden has become more specific and widely used in family caregiving research (Dunkin & Hanley, 1998), different aspects of caregiving burden experienced by family members including physical, psychological, social, and financial problems are emphasised and studied, using a standardised instrument such as the Family Burden Interview Schedule used in this study (Chou, 2000; Schene, Tessler & Gamanche, 1994). This is an important outcome measure in intervention studies for family caregivers of patients with chronic and mental illnesses (Chien & Norman, 2004).

Because individual caregivers respond differently to the stressors of caregiving situations, researchers have identified factors that affect the relationship between the demands of care and carers' burden and distress. These factors mainly include patient's symptoms, functional status and duration of illness (Cook, Lefley, Pickett & Cohler, 1994; Cuijpers, 1999), and caregiver's characteristics such as age, gender, hours of weekly contact with patient, and kinship relations (Reinhard, 1994). Reported mediating

factors include social support and coping skills (Solomon & Draine, 1995). In addition, family variables such as dysfunctional family roles and relationships, problematic communication patterns, family conflicts and incongruence of family members' appraisal of patient can also exacerbate caregiver burden (Lemmens et al., 2003). As suggested by Maurin and Boyd (1990), the beliefs that family members have about what influences events and situations during the course of schizophrenia are also important factors in determining how well family caregivers cope with caring for the patient.

One limitation to the concept of family burden is its connotation of negative emotions, whereas many caregivers find their role fulfilling and uplifting (Bland & Darlington, 2002). The dissonance between objective burden and subjective satisfaction with the caregiving experience has been noted in the literature (Martens & Addington, 2001), and has resulted in the suggestion that the 'experience of caregiving' or 'psychological well being' of family carers should replace the use of 'caregiver burden'. However, the negative effects of caregiving on family functioning, daily routines, and their physical and psychological well being for family members of patients with severe mental illness are noteworthy, and most importantly the false beliefs about and social stigma towards mental illness in Chinese and other Asian countries (Ma & Yip, 1997; Meredith et al., 1994). Therefore, although there is no widely accepted theoretical framework of family burden, it is important to understand that caring for a relative with schizophrenia and other severe mental illnesses imposes a feeling of burden on family caregivers (Rungreangkulkij & Gilliss, 2000).

2.2.2 Importance of family focused intervention for patients with schizophrenia

There are several reasons for providing interventions to families of people with schizophrenia. First, studies on expressed emotion, which refers to the critical or emotionally over-involved attitudes and behaviour displayed by one or more family members to their relative with schizophrenia (Kavanagh, 1995), has revealed that family dynamics and emotional climate affect the reoccurrence of positive symptoms and therefore the course of the illness (Butzlaff & Hooley, 1998). While the mechanisms of action of high expressed emotion in the course of schizophrenia are unclear, it is clear that a high level of distress is inevitably experienced by a patient who is in regular and

frequent contacts with such family members (Mueser & Gingerich, 1994; Repper & Brooker, 1998). However, the education and involvement of these family members in the planning and implementation of treatment can only benefit the monitoring of progress of treatment and changes in patient's condition. Enhanced ability of family members to detect any warning signs of relapse, and notifying health professionals about such signs, can be crucial in preventing these illness relapses. There have been reports of long delays in treatment due to inadequate family support (Barnes et al., 2000; Drake et al., 2000).

Second, having an intimate relationship with a relative with schizophrenia and providing care for such a person can induce a great burden on family members. Families, if used as a 'dumping ground' for these patients, may be overwhelmed by the challenges and difficulties in managing a patient with schizophrenia (Iodice & Wodarski, 1987), even though there are some positive aspects of caregiving such as a sense of inner strengths and satisfaction, personal growth and enhanced family relationship (Greenberg, Greenley & Benedict, 1994; Winefield & Harvey, 1994). Reducing caregiver burden is an important goal of family support and care that can help family members remain involved with their loved ones while maintaining their own psychological and physical well-being (Mueser, 2003).

Lastly, high levels of stress within a family, which may arise from caregiver burden, can have a negative effect on a patient's illness, increasing their vulnerability to relapse (Butzlaff & Hooley, 1998). The intimate relationship and interactions between patients with schizophrenia and their family members warrants application of family-centred interventions for improving the ability of families to work with their patient to cope more effectively with stress relating to caregiving from within and outside the family (Mueser & Glynn, 1999).

Families were once scapegoated as a major causative factor of the pathogenesis of schizophrenia (Lefley, 1996), but the weight of evidence today is that families can play a vital role in helping their relatives with schizophrenia make good progress towards their recovery (Mueser, 2003). Working with families would appear to be one effective way of delivering community-based intervention to the patients. Nevertheless, families need adequate support themselves if they are to support their disabled relative. To enhance family support and care for patients with schizophrenia, there have been increased

research studies in developing and testing different modes of family intervention over the past 20 years. The following section draws on the literature on the development and major types of family intervention for patients with schizophrenia and their theoretical basis and looks at the evidence supporting their relative effectiveness for these patients and their families.

2.3 DEVELOPMENT OF FAMILY INTERVENTIONS

Treatments for patients with schizophrenia reflect dominant ideas on the causes of the illness. The origins of family intervention can be traced to theories of family causation of the illness, which go back to the 1940s and 1950s. In the 1950s, research on dysfunctional communication in families originated from the idea of the 'double bind' (Bateson et al., 1956), which occurs when an instruction is given overtly to a patient by family members, but is contradicted by a second more covert instruction. As suggested by Bateson, this 'double bind' communication leaves the child able to make only ambiguous or meaningless responses, and schizophrenia was thought to develop when this process persists. Studies of communication in families of patients with schizophrenia have indicated rather inconsistent and conflicting findings (Hirsch & Leff, 1975), the disordered family communication and role relationships are considered to be important factors associated with the course of the illness and patient's recovery.

In the late 1950s, the theory of expressed emotions (EE) was developed in an attempt to describe emotional attitudes of family members towards patients with schizophrenia and its relationship with the illness. The concept of EE was developed by Brown et al. (1962) and measured with a semi-structured interview schedule (Camberwell Family Interview) on three dimensions: criticisms, hostility and emotional involvement. This EE concept has proven useful for understanding the interactions within families with a member suffering from schizophrenia. A meta-analysis by Butzlaff and Hooley (1998) of 27 studies of the EE-outcome relationship with schizophrenia in the US and other Western countries, confirmed that EE is a significant and robust predictor of relapse in schizophrenia (i.e. the weighted mean effect size was 0.31), particularly for those primary family caregivers with high face-to-face contact with the patient. More evidence continues to accumulate highlighting the link between health status of patients

and family caregivers and family relationships (Cole & Reiss, 1993; Wearden et al., 2000).

Leff et al. (1985) using a combination of support and education for family members managed to successfully lower expressed emotion in families and thus positively reduce patients' relapse rate (i.e. 14% relapse in family support group vs. 78% in control group with regular medications over two-year follow-up). Since then, EE related research has focused not only on the patient's relapse but also on the effect of caring on the whole family. Karanci and Inandilar's (2002) study of coping and distress of caregivers of Turkish patients with schizophrenia indicated that caregivers' perceptions of their ability to cope with patient's symptom behaviours such as aggression and antisocial behaviour, and their reported distress due to these behaviours are closely related to their EE level. Similarly in the UK, Budd, Oles and Hughes (1998) studied the relationship between caregiver burden and coping style in 91 carers of patients with schizophrenia and reported that emotional over-involvement and criticism are associated with higher levels of family burden. It has also resulted in various therapeutic and educational strategies aimed at reducing family caregivers' EE in order to improve patients' illness and symptom intensity, and thus reduce relapse rates.

A long-standing theoretical rationale underlying the use of family-centred interventions comes from studies in the West, which have reported consistently that patients with schizophrenia who live in families that have high levels of EE have relapse rates three to 10 times greater than those who live in low EE families (Bebbington & Kuipers, 1994; Ivanovic, Vuletic & Bebbington, 1994). Studies on EE also showed that the role of family attitudes and interactions influenced the course of schizophrenia, but there was insufficient evidence that it influenced onset of the illness, as might be predicted by the stress-vulnerability model (Kavanagh, 1992; Barrowclough & Johnston, 1996; Kavanagh, 1992; Wearden et al., 2000). Barrowclough and Parle (1997) suggest that critical factors common to successful psychosocial intervention for schizophrenia include helping the family, especially those with high levels of EE, to reduce their negative attitudes towards patient's illness and increase their confidence in coping with patient's symptoms and bizarre behaviour.

Family intervention techniques have developed gradually and become accepted as an alternative to biomedical or pharmacological treatment for changing families' attitudes, relationships and communication patterns. However, even up to the late 1970s, family theories and therapies for schizophrenia were supported by little empirical evidence. Most studies showed disappointing, non-significant or modest results, which contrasted with over-ambitious claims for the efficacy of family therapy. Anderson and Adams (1996) and Dixon et al. (1999) suggest that in the West, there are difficulties in employing family intervention in everyday clinical practice with groups of patients with schizophrenia in receipt of community care, due to inadequate mental health care services, staff training and resources. Research in the 1980s has already indicated that information and caregiving skills learning were important but were too frequently unavailable as a community resource for patients and families (Noh & Turner, 1987). A field study in the US (Dixon et al., 1999) also found that less than one-third of patients who have contact with their families reported that their families had received information, support, or advice about their illness and less than 10% said that their families had attended an educational or supportive programme. Ma and Yip (1997) suggest similar reasons to explain why family intervention has not been frequently used in community-based treatment for patients with schizophrenia in Hong Kong.

In spite of inadequately trained therapists, research over the 1980s has established a more sound evidence base on the effects of family environment for schizophrenia, especially for those families with highly critical or emotionally over-involved attitudes towards patients. With much increased interest and understanding of the importance of the role of the family in caring for patients with schizophrenia in the community, there have been very positive advances in the development of different types of family intervention in parallel to psychosocial intervention for patients with schizophrenia, over the last 15 years (Brooker, 2001; Mueser, 2003). Demands for family interventions within the community have also increased substantially as a result of changes in the organisation of mental health services over the past decade in Western countries (Budd & Hughes, 1997), and also in Hong Kong. It is beyond doubt that the current emphasis on community care and caring for the carers has made family intervention a crucial component of the treatment plans for patients with schizophrenia. Wide dissemination of

an effective model of family intervention is a priority for improvement of contemporary community mental health services.

Pharoah et al. (2001) and Pilling et al. (2002) in their meta-analysis of controlled trials of family interventions involving over 2,000 patients with schizophrenia (from 1980 to 1999), in different countries such as the US, UK, Australia, and mainland China, concluded that all types of family intervention (both single and group format) are more effective in reducing patient relapse up to one year, readmission up to two years and rates of treatment compliance, when compared to standard care. As recommended by the American Psychiatric Association (1997) and Schizophrenia Patient Outcomes Research Team (Lehman, Steinwachs & the Survey Co-investigators of the PORT project, 1998), which was funded by the National Institute of Mental Health in the US, patients who have ongoing contact with their families should be offered a family psychosocial intervention that spans at least six months and provides a combination of education about the illness, family support, crisis intervention, and problem-solving skills training. In addition, the team suggests that family intervention should not be restricted to patients whose families are identified as having high levels of expressed emotion. Similarly, the National Institute for Clinical Excellence in the UK in its clinical guideline of core interventions in the management of patients with schizophrenia, suggests that family intervention should be available to the families who are living with or who are in close contact with patients with schizophrenia (National Collaborating Centre for Mental Health, 2002).

Nevertheless, the past decade has witnessed rapid growth of a variety of family intervention strategies, which have been largely influenced by cognitive-behavioural and stress and crisis theories. Single or multiple-family group intervention programmes, and those consisting mainly of education, behavioural and supportive components, have been used in the treatment of people with a variety of chronic mental health problems such as depression, anxiety disorders (Anderson et al., 1986), dementia (McCallion & Toseland, 1995), and eating disorders (Dare & Eisler, 2000). However, different terms are used to refer to work with families, such as psychoeducational, psychosocial, family education, family management, family support, or combinations of these terms. In the absence of agreed terminology, the guidelines suggested by Fadden (1998) in the research update on

family interventions may be helpful. Fadden suggested that the terms psychosocial, psychoeducation and behavioural management approaches to family interventions, generally refer to those interventions in an individual or group format, where patient and family members meet together, where there is a component of skills acquisition in addition to a didactic teaching element; and the primary aim of the programme is to reduce patient relapse and readmission. He also suggested that family education, consultation, support, and counselling and relatives' groups usually refer to interventions directed at family members (excluding the patient); and their primary focus is on the needs of family members. Fadden's suggestions are helpful in providing a background to the description of the major types of family intervention and their relative effectiveness for families of patients with schizophrenia, which follows.

2.4 TYPES OF FAMILY INTERVENTION AND THEIR EFFECTIVENESS

Four board modes of family intervention are frequently used in the West and mainland China to address specific treatment outcomes including reduction of patient relapse and family burden and improvement of family and patient functioning. These modes include: family psychoeducation, behavioural family management, multiple-family group intervention, and family consultation or supportive counselling. The following sections define, describe and discuss the empirical bases of these four modes of intervention and compare their relative effectiveness based on the literature over the past 20 years (i.e. the literature search strategies for these family interventions are presented in Appendix 1).

2.4.1 Family psychoeducation programmes

The psychoeducational model of family care conceptualised by the pioneers focused on the plight of people with mental illness, particularly on higher risk of relapse and re-hospitalisation, at great cost to the patient and to society as a whole (Anderson, Reiss & Hogarty, 1986; Falloon, Body & McGill, 1984). These researchers posited that family behaviour played an important role in patient functioning and that families could be educated to create an environment in which relapse could be reduced. Family psychoeducation is the most frequently used model of family intervention for patients

with schizophrenia in Western countries as well as in Asian countries (Dixon et al., 2000). In the 1980s, these programmes of family intervention were initiated in response to the effect of expressed emotion in families of patients with schizophrenia on patient relapse, assisting these family members to enhance their ability to cope with the illness (Dixon, Adams & Luckstead, 2000). Over the past 20 years, several modes of family psychoeducation for schizophrenia have been developed and empirically tested. The theoretical foundations for these interventions are mainly derived from stress and coping models and other psychological theories such as cognitive-behavioural, social learning and crisis theories (Lukens, Thorning & Herman, 1999). According to Lukens and his colleagues, psychoeducational intervention grows naturally out of the framework of stress reduction and adaptation, because it implies that to cope with difficult family caregiving situations, family members need knowledge, coping skills and adequate psychosocial support. Since psychoeducation interventions focused mainly on the patient's mental condition, studies in family psychoeducation have given limited attention to family burden and to family perceptions of problems and needs (Hatfield, 1994).

While family psychoeducation is broadly used to characterise a range of approaches of educational intervention for families of patients with schizophrenia, there are several features common to the effective ones, including structural components, philosophical perspectives and goals and content of the programmes. First, their common structural components are that the programmes are designed and led by health professionals; they are long-term, lasting between nine months to two years; they are an integral part of the patient's treatment plan along with medication and other psychiatric treatments; they may be delivered to single or multiple families at the patient's home or in a clinical setting; and they include both the family members and the patient during the sessions of intervention (Dixon et al., 2000). Second, the philosophical perspectives of these interventions are common in the emphasis on the here-and-now circumstances and improving the future, while avoiding delving into the past and imposing blame (Mueser, 2003). The treatment team seeks to establish a collaborative relationship with the family in order to share the burden of managing the illness and working towards patient recovery. Lastly, in terms of goals and content of the programmes, all focus on providing

information about the illness and its treatment, management of patient's illness behaviour, problem solving and coping skills in caregiving, and access to family support services (Lehman et al., 1998). Such information is crucial for family caregivers to cope with the caregiving role.

2.4.2 Behavioural family management

Behavioural family management (BFM) for patients with schizophrenia was developed by Falloon, Liberman, Lillie and Vaughan (1981) in the USA using family education, training in communication skills and practice in problem solving. This programme delivered in the context of multiple-family groups and held for 10 sessions over a three-month period, showed beneficial effects on patients (Falloon & Liberman, 1983). This intervention has been refined, elaborated and implemented across a wide variety of socio-economic and cultural groups in the US, UK and mainland China (Falloon et al., 1985; McFarlane et al., 1995; Montero et al., 2001; Xiong et al., 1994), proving effective in reducing symptoms, promoting remission, strengthening social functioning, and reducing family burden. This intervention is based on a functional analysis of the family and the application of learning principles and problem solving techniques to help family members learn how to manage patients with schizophrenia in collaboration with mental health professionals (Falloon, Boyd & McGill, 1984). As the behavioural approach assumes that patient, family, therapist, and other elements of the mental health services are interactive and open to change at different levels, families of patients with schizophrenia should be assisted to understand their own specific needs at different points of time for comprehensive and continuous care of the patients (Hatfield, 1994). Behavioural family therapists conduct ongoing thorough assessments of the needs, assets, deficits, burden, stress and desires of these family members and assist them in setting goals of learning to better cope with caregiving, solving problems and communicating more directly and constructively with patient and other family members.

BFM has been operationalised to the point where its procedures are now available in a detailed and clearly described treatment manual and a workbook, which serves as the foundation for the family's effective management of the illness. Different modes of the

BFM programme range from 10 to 20 sessions and span from six months to two years (Mueser & Gylnn, 1999).

According to Mueser and Gylnn (1999), the BFM programmes consist mainly of six components: engaging (introduction of the programme and exploration of the benefits of family work, followed by initial discussion about family problems), assessment (individual interviews with family members to gather information about the illness, family background and their personal goals of participation in the programme from each family member's perspective and to establish a trusting relationship with the therapist), psychoeducation (information about the illness, treatment, medication compliance, role of family in caregiving, and improvement in patient's independence and recovery), communication skills training (improvement of the ability of family members to communicate in direct, effective, and non-stressful ways), problem solving training (teaching family members a standardised approach for helping them face problems in caregiving and collaboratively identifying alternative solutions to the problems), and termination phase (discussion of families' accomplishments, community resources and future plan).

2.4.3 Multiple-family group interventions

Multiple-family education groups are professional-led intervention in group format aimed at providing continued education and support for people with schizophrenia and other severe mental illnesses and their family members, and are usually provided on a time-unlimited basis (Mueser & Glynn, 1999). These groups are more economical than single-family educational intervention and consultation, providing more opportunities for social support among participants, and providing a forum for continued psychoeducation about the nature and management of schizophrenia (Mueser, 2003). However, there are different types of multiple-family groups, such as family-dynamic multi-family groups in New Jersey (Marsh, 1994; McFarlane et al., 1995), and family-aided assertive community treatment in New York (McFarlane, Stastny & Deakins, 1992; Stein & Santos, 1998). Most of them are based on the family psychoeducation or behavioural model, but each intervention has its emphasis on the techniques and objectives of intervention. For example, the family-dynamic multi-family groups (Marsh, 1994)

emphasised opening intra-family communication, sharing emotional responses and attempting to resolve family conflicts. The therapists did not provide any education about schizophrenia and medication compliance, and did not use any structured problem solving techniques. The family-aided assertive community treatment integrated systematic and ongoing family psychoeducation or family crisis intervention and intensive case management approach (McFarlane et al., 1992), targeting specifically the less-treatment-responsive group of patients with schizophrenia. Supportive Family management developed by Zastony, Lehman, Cole and Kane (1992) in New York for a highly treatment resistant population of young adults with chronic schizophrenia provides patients and families with detailed information about the illness and treatment plan, and direct advice to families concerning linkage to community resources and management of crises and day-to-day patient and family difficulties. Brief family therapy techniques are also employed to support the families when indicated and make them treasure their caregiving role.

As suggested by McFarlane (2002) and Mueser (2003), multiple-family groups are guided by five important goals: (1) educating family members about mental illness and its treatment; (2) establishing and promoting social support for patients and families; (3) training in problem solving skills to address common difficulties and distress; (4) sharing and practising patient management strategies; and (5) providing information of and access to community resources and consultation for family support.

2.4.4 Family education, consultation or supportive counselling

Family consultation, sometimes called supportive family counselling, is an individualised approach of support and education to a family member or the whole family of a patient with schizophrenia (Bernheim, 1982; Marsh & Johnson, 1997). It focuses on the adaptive strengths of a family rather than its pathology and deficits. The consultant may be either a health professional with expertise in family counselling or a trained family member, and provides information and advice to family members as needed on the mental illness, mental status assessment, mediation strategies, problem management, and referrals to community resources (Marsh & Johnson, 1997). The intervention is a flexible approach, which is collaborative between family and consultant to determine the goals

and plan of actions; and it is a very short-term educational intervention for families whose ill relatives refuse or resist treatment (Bernheim, 1987).

Similar to other family consultation programmes, Solomon et al.'s (1996) study reported an individual family consultation conducted by the Training and Education Centre Network in the US, a collaborative initiative of mental health professionals and family members experienced in providing family education to individuals with a mentally ill relative. The programme provided a minimum of 6 hours of consultation to each family, including a 2-hour assessment, at least 2 hours of face-to-face contact, and at least 2 additional hours of either face-to-face or telephone contact. The maximum amount of service was 15 hours. Families determined the focus of their education with their consultant and could contact the consultant on an as needed basis. Generally, family consultation is a time limited intervention, from two to three months and from 15 to 30 hours of contact with the family, and thus is only focused on one or two specific objectives. As suggested by Solomon (1996), this intervention is effective in improving families' knowledge of or insight into the illness and medications as well as patients' medication compliance.

Family education programmes, either in individual or group format, are usually of short duration (from one day to less than six months) and focus on providing families of people with schizophrenia with information on mental illness and advice on its management (Biegel, Robinson & Kennedy, 2000). This type of intervention may be led by mental health professionals or by trained peer leaders. Family education also adopts a strengths perspective, in which families are encouraged and assisted to develop their stress management and coping skills and to improve their psychological well being and ability to adapt to dealing with their relative's illness (Solomon, 2000). Many of the family education programmes have been developed by families in response to their dissatisfaction with the information and support that health professionals offered to them; and these families often feel that they need practical, hands-on assistance with day-to-day problems instead of only standardised medical treatment and care (Hatfield, 1994)

2.4.5 Commonalities of different modes of family intervention

Most recently developed family intervention programmes begin with a few teaching sessions, which cover basic information on the aetiology, symptoms, medical

and psychological treatments, and prognosis of schizophrenia (McFarlane, 2002; Pilling et al., 2002; Hazel et al., 2004). Intervention approaches then differ in subsequent sessions over content, format, duration, and the time intervals between sessions. As suggested by the Schizophrenia Patients Outcomes Research Team in the US (PORT, 1998), family education and support programmes are usually organised around the central theme of providing family members of people with schizophrenia with education about the illness and its treatment, guidance and resources for patient care and for family carers during crisis, and training in managing common problems in caregiving. Even though different techniques or approaches are used, family interventions for schizophrenia aims to achieve some common goals, including: (1) working in alliance with families who care for the person with schizophrenia to identify stressors associated with family dysfunction and patient relapse; (2) enhancement of problem anticipation and problem solving; (3) improvement of family atmosphere by reduction of high emotional involvement and critical attitudes towards the patient by their family such as hostility and criticism; (4) setting realistic expectations on patients' social, vocational and performance in the home; (5) helping families improve communication and relationship with patients; and (6) attainment of desirable change in family members' behaviour and understanding of the illness and its care (Pharoah et al., 2001; Thornicroft & Susser, 2001). However, little is known about the therapeutic value of different components or strategies (Dyck et al., 2002). With better understanding of these crucial therapeutic elements within family intervention, it may be possible to develop a more consistent, reliable and effective family intervention programme for patients with schizophrenia.

In addition, two reviews of family intervention studies (Dixon et al., 2000; Solomon, 2000) suggest that there are several characteristics common to the four modes of family intervention mentioned above (Section 2.4.1 to 2.4.4): being delivered and led by health professionals such as nurses, social workers and psychiatrists; primary focus on patient outcomes such as relapse and medication compliance with family outcomes as secondary; main components including information about the illness, its medication and treatment and strategies on patient management; involving all interested family members, including the patient; long-term intervention is more effective (e.g. at least six months);

and exclusion of any beliefs and concepts which presume families are the causal agent of the development of schizophrenia.

2.5 RELATIVE EFFECTIVENESS OF DIFFERENT MODES OF FAMILY INTERVENTION

A number of reviews from the mid 1990s have highlighted the possible advantages of family interventions for people with schizophrenia conducted in several countries such as the US, the UK and other European countries, and mainland China, such as Barbato and D'Avanzo (2000), Mari and Streiner (1996) and Pilling et al. (2002). Among the different models of family intervention in schizophrenia, psychoeducation (e.g. Hogarty et al., 1991) and behavioural family management programmes (e.g. Falloon et al., 1982) have been the most extensively studied modalities. More recently needs-based psychosocial interventions (e.g. Sellwood et al., 2001) have been established with specific consideration of individual family needs.

However, there were some exceptions, namely trials mostly undertaken in 1970s and 1980s, using models such as crisis intervention model by Goldstein et al (1978) and psychodynamic model by Kottgen et al. (1984). These models demonstrated negative or non-significant effects when compared with standard care (Leff et al., 1982; Levene et al., 1989) or psychoeducation intervention (McFarlane et al., 1995), and evaluations suffered major methodological limitations such as small sample size, non-equivalent or no control group, and case study design.

A relatively recent systematic review of controlled trials between 1978 and 1996 by the Cochrane Schizophrenia Group (Pharoah et al., 2001) suggests that most psycho-education and supportive approaches of family intervention have consistently demonstrated positive effects on reducing patients' relapse rate and improving patients' medication compliance and families' knowledge about the illness. The specific effects of family intervention on family members' psychosocial needs, such as family functioning, coping with caregiving, psychological distress and burden of care, and management of patient within the home environment, have not been studied adequately and so data are few and equivocal. However, those few studies (Falloon et al., 1982; Tarrier, 1991; Xiong et al., 1994), which have included an economic evaluation, suggest that

psychoeducational or behavioural family intervention is more cost-effective than the conventional mental health care services.

When comparing the effects of different models of family intervention on patient and family outcomes, studies in mainland China (Xiong et al., 1994; Zhang et al., 1994), the UK (Tarrier et al., 1994) and other Western countries (Dixon et al., 2001; McFarlane, Dixon, Lukens & Lucksted, 2003), have consistently demonstrated that family psycho-education and/or behavioural approaches of intervention spanning at least 10 sessions over six months is more effective and shows relatively long-lasting effect (more than three years) on the prevention of relapse among people with schizophrenia, than individual psychosocial treatment or medication alone. However, the psychoeducation and behavioural approaches of intervention, as described by researchers in previous studies, consisted of a variety of content, format and techniques. The common elements in several approaches of effective family psychoeducation programmes include social support, education about the illness and its treatment, guidance and resources during crisis, and training in problem solving (Dixon et al., 2001; Lehman & Steinwachs, 1998). However, little is known about the major therapeutic components of psychoeducation and other psychosocial family interventions for schizophrenia (Barbato & D'Avanzo, 2000).

2.5.1 Evidence on effectiveness of family psychoeducation

Over the past 20 years, the psychoeducation approaches of family intervention has been used most frequently and evaluated in trials to be most efficacious in Western and Asian countries, and the findings of these studies add to our knowledge of family intervention and some specific points are important for research and practice. First, when compared with other models of family intervention, psychoeducation intervention is most effective in reducing patient relapse and readmission; this finding is robust across cultures (e.g. Leff (1994) in the UK; Xiong et al. (1994) in mainland China; McFarlane et al. (1995) in the US; Canive et al. (1996) in Spain; Chou, Liu & Chu (2002) in Taiwan), sustainable over time and up to eight years (Tarrier et al., 1994), and can reduce costs of care (Xiong et al., 1994).

Second, offering psychoeducation to multiple families in groups and including the patients, has been found to be highly effective, especially when some patients have florid positive psychotic symptoms (McFarlane, 2002; Pilling et al., 2002). However, there are

two important issues that the service providers should consider;, multiple-family groups may have very high non-compliance or attrition rates due to group members time constraints on attending groups in relation to work and domestic life and the inconvenience of transport and meeting times; also they man not be able to temporarily settle the patient in a safe place and arrange alternative care for the patient when attending the group (Vaughan et al, 1992; Chien, Chan, Morrissey & Thompson, 2004); and running a family group requires a highly skilled and experienced therapist who can effectively manage numbers of patients with active psychotic symptoms and disturbing behaviour and their highly distressed family carers (Fadden, 1998).

Third, the focus of intervention is usually on family education and problem solving skills training so as to develop families' coping skills with day-to-day problems. Studies comparing family psychoeducation with psychodynamic or counselling approaches indicate that psychoeducation intervention is more effective in improving families' knowledge and coping skills for caregiving (Vaughan et al., 1992; McFarlane, 1994). However, providing information or education alone without a skills training component only benefits family carers' satisfaction with mental health services, and increases their knowledge about the illness and its treatment (Posner et al., 1992), but has been shown to have only a short-term or non-significant effect on patient relapse (Dixon et al., 2000). Family education is likely to be an important component for engagement of families in the intervention, and is best provided in the early stage of the illness when families can be assisted to develop correct concepts of the illness and positive beliefs of caregiving (Sidley, Smith & Howells, 1991).

Finally, brief crisis-oriented family psychoeducation (Leff, 1994; Linszen et al., 1996) focusing on stress management and problem solving is more likely to be effective on families' coping ability and patients' symptom control, for families with low expressed emotion and those of patients with first psychotic episode when compared with detailed, lengthy psychoeducation or behavioural intervention.

2.5.2 Evidence on effectiveness of behavioural management programmes

Following Falloon et al.'s (1982) work on manual-driven behavioural family therapy for people with schizophrenia under community case management in the US which showed a positive substantial effect on patient relapse and symptom control, there

is now considerable evidence that different modes of problem-focused behavioural family interventions for patients with schizophrenia result in reduced relapse over one to two years follow-up (Pharoah et al., 2001; Sellwood et al., 2001). Tarrier et al. (1989) conducted a controlled trial in the UK comparing the effect of a nine-month behavioural family intervention with a short educational programme or routine treatment, which indicated that patient relapse within the behavioural intervention group was significantly lower than that of the other two groups at two-year follow-up. The findings of Berglund, Vahlne and Edman's (2003) study in Sweden also supported that the behavioural family intervention reduced patient relapse and family burden and negative attitude towards caregiving, when compared with conventional family support. A more recent trial of a needs-based and behavioural family intervention using Barrowclough and Tarrier's (1992) approach in the UK (Sellwood et al., 2001), indicated that family intervention based on a formal assessment of the family carer's needs was more effective in reducing patients' relapse and carers' needs and improving patient functioning and positive symptoms over one-year follow-up, when compared with routine family support and patient care. However, the researchers concluded that there were limited significant benefits for family carers participating in the behavioural intervention, as well as no improvement in patients' medication compliance.

Telles et al. (1995) compared the effectiveness and cross-cultural applicability of Falloon's behavioural management programme and standard case management in symptom reduction, functional status and illness relapse of 40 low-income Spanish-speaking people with schizophrenia in the USA over one-year. The results of this evaluation did not support the positive findings from previous studies when applied to a socio-cultural diverse population. Hence, socio-cultural factors may influence family members' responses to different types of family intervention. These findings also raise the question of whether a behavioural family management programme can be applied effectively to socio-culturally diverse populations.

The Treatment Strategies for Schizophrenia study (Schooler et al., 1997) in a sample of more than 200 patients with schizophrenia in the US reported that there was no significant difference in patients' medication compliance and readmission over 24-month follow-up between behavioural family intervention and supportive multiple-family group

intervention, although both approaches appeared to have a positive effect on these outcomes. Bellack, Gretchen, Schooler and Janine (2000) continued the Treatment Strategies for Schizophrenia study, and reported that the intensive behavioural intervention did not result in a more significant improvement in family communication and problem solving ability than supportive family intervention over the two-year study period.

Similarly, Zastowny, Lehman, Cole and Kane (1992) in New York also reported that behavioural family treatment following Falloon's approach did not show significantly greater improvements in patients' functional status, symptom control and re-hospitalisation and families' burden, functioning and problem solving, than that of supportive family management developed by Bernheim and Lehman (1985). Consistent with the findings of these studies, several recent reviews have raised questions about the importance of behavioural skills training and the mechanisms of therapeutic actions of family interventions and other psychosocial interventions (Dixon et al., 2000; Pharoah et al., 2001). Given the higher cost of intensive training and procedures of a behavioural family management programme, Bellack et al. (2000) in their study of the effects of behavioural family management on family communication and patients' relapse and symptom management suggested that less intensive, educational or supportive family interventions which can demonstrate similar positive effects for patients and families should be used in order to ensure choosing the more cost-effective family intervention for the patients. Although these studies do not support behavioural family management as being more effective than supportive and educational approaches of family intervention, it should be noted that these studies did not include a control group (standard care) for comparison of their relative effectiveness.

Overall, past studies in Western countries indicate that behavioural family intervention can produce significant positive effects on patient outcomes such as relapse and symptom control but there were no significant positive effects on family carers' psychosocial conditions and problem solving. As suggested by reviews of trials in family interventions for people with schizophrenia (Barbato & D'Avanzo, 2000; Bustillo et al., 2001), behavioural family intervention, which consists of a clearly defined set of behavioural techniques following a step-by-step skill building format and is conducted by

an intensively trained professional, may not produce better patient and family-related outcomes, when compared with other family educational and supportive interventions. There is no published study on behavioural family intervention within the Chinese population.

2.5.3 Evidence on effectiveness of multiple-family group interventions

In the 1980s, multiple-family group (MFG) interventions for people with schizophrenia were implemented in combination with different educational and behavioural approaches, but there were limited empirical trials of their effectiveness on patient and family-related outcomes. The recent commonly used format of multiple-family group for people with schizophrenia – an ongoing, closed, long-term group led by at least two clinicians, involving both patients and their families, has been evaluated in a few clinical trials by McFarlane and his colleagues in the US in the 1990s. These studies demonstrated that multiple-family group interventions using psychoeducation and/or behavioural approaches, for first-episode and high-risk patients with schizophrenia or patients with highly stressed families, are consistently more effective to improve patients' relapse and employment rate than single-family interventions. These positive patient outcomes of multi-family intervention increase with time, up to four years. McFarlane, Link, Dushay and their colleagues (1995) conducted a three-group comparison between psychoeducational MFG, psychoeducation in a single-family format and MFG (mainly discussion and sharing facilitated by two clinicians during group meetings) without psychoeducation for 41 inpatients with schizophrenia, using symptomatic relapse as the main outcome criterion. The respective relapse rates at four years were 50%, 78% and 57%, and the two MFGs reported similar relapse rate per year (12.5% for psychoeducational MFG and 14% for MFG without psychoeducation). These results indicate that when combined with antipsychotic medication, the MFGs with two different formats can produce longer term and more positive effect on patient relapse when compared with the single-family psychoeducation group. Another clinical trial conducted by McFarlane, Stastny and Deakins (1992) examined the relative effect of psychoeducational MFG combined with assertive community treatment (termed Family-aided Assertive Community Treatment, FACT) and single-family crisis intervention (SCI) for 68 patients with schizophrenia on their employment, re-hospitalisation,

symptoms (positive and negative), medication compliance, and family burden and well-being over two-year follow-up. The psychoeducational MFG resulted in a significantly higher employment rate over two years (32% versus 19% for SCI). While there were no significance differences between the two groups on the other four outcomes, the two groups demonstrated similar significant improvements in these four aspects over the two years (about 38% of the baseline symptom severity, a reduction of chlorpromazine equivalents from 975 mg to 696 mg, an increase in median medication compliance from 75% to 100%, and improvements in families' ratings of objective and subjective burden).

The New York Family Psychoeducation Study compared a MFG and a single-family intervention over two years at five state psychiatric hospitals and one city hospital, using a large representative sample of patients with schizophrenia (Marsh, 1994), and reported that the patients' relapse rate for the MFG was exactly one-third less than that of the single-family intervention (27.7% versus 41.6%). In addition, the Caucasian patients in the MFG who did not fully remit on medication and had a family member with high expressed emotion, displayed a significantly lower relapse rate than those in the single-family intervention group (9% versus 56%) and the African American patients in the two interventions (42% for MFG and 22% for single-family intervention). Mean dosage of antipsychotic medication in the MFG decreased over two years, whereas the mean dosage increased in the single-family intervention. The consistent positive effect of MFG on patients' relapse reported in these studies regardless of the content and approach of intervention used, may be explained by the expansion of families' social network and increase of peer support resulting from group participation. Further research is needed to examine the importance of social support and other therapeutic components in the MFG intervention.

Hazel et al. (2004) in the US compared the effects of a MFG treatment (n = 53) using McFarlane's approach and standard care (n = 44) for people with schizophrenia or schizoaffective disorder and demonstrated that the MFG significantly reduced family caregivers' distress, when compared with standard care over two years. However, there were no significant differences in families' psychosocial support resources between the two groups after two years. This may be due to the limited amount of time per month the participants were involved in multiple-family group treatment, which was not sufficient to

allow for a significant increase in social support. Moreover, as pointed out by McDonell et al. (2003), multiple-family psychoeducation groups for patients with schizophrenia might not reduce family burden because the group intervention focused on patients' illness management and recovery, but not family caregivers' psychological well being and support resources.

As a result, there is relatively less research reporting that MFG intervention for people with schizophrenia indicates greater positive effects on family-related outcomes such as burden and other psychosocial functioning than other modes of single and multiple-family interventions. Among a few studies supporting the benefits of MFG to family caregivers, Dyck et al. (2000) at Spokane, Washington demonstrated a more postive effect of a psychoeducational MFG using McFarlane's approach for 63 outpatients with schizophrenia at a large community mental health centre on caregivers' physical health compared with standard care. A lower percentage of caregivers in MFG (23%) visited their physicians more than once, compared with the standard care group (31%), over the 12-month follow-up period. Results of stepwise regression analysis also indicated that treatment group, together with onset of illness and number of pre-intervention physician visits predicted the number of post-intervention physician visits ($p < 0.05$).

However, other clinical trials in Western countries indicate that there is no significant difference between multiple-family group intervention and single-family mode of intervention for people with schizophrenia on both patient and family-related outcomes such as relapse rates and patient and family functioning. Leff et al. (1990) in London, UK also conducted a trial to compare the effect between an individual family therapy (12 families and including patients), a supportive family education group (11 families and excluding patients) and routine care for patients with schizophrenia in families with high expressed emotion. Patients' relapse rates in the individual family therapy and supportive family group (33% and 36%) were similar and significantly lower than the families under routine care (about 75%) at two-year follow-up. In Hogarty et al.'s (1997) psychoeducational MFG study using Anderson, Reiss and Hogarty's (1986) approach (versus a single-family personal therapy, a single-family supportive therapy, and a combination of MFG and personal therapy) for 97 patients with schizophrenia or

schizoaffective disorder in the US, those patients receiving personal therapy alone showed a significantly lower psychotic relapse rate (28%) than either the supportive therapy or family therapy patient (38% and 45%), over three-year follow-up. However, 13 of 15 treatment-related terminations among the patients living with family occurred in the non-personal-therapy arms, particularly in the supportive therapy condition, thus limiting survivorship to less representative and possibly less vulnerable patients in these no-personal-therapy conditions.

In addition, some clinical trials in the US and UK demonstrate that there are no significant differences between different approaches of multiple-family group intervention for people with schizophrenia on patient and family-related outcomes. Zastowy et al. (1992) and Schooler et al. (1997) in the US compared the effects of two approaches of multiple-family group intervention, Falloon's approach of behavioural family management and supportive counselling with educational workshops, on patients' relapse, re-hospitalisation and dosage of antipsychotic medication over two years. The findings of these two studies indicated that there were no significant differences in patients' relapse and dosage of medication between the two approaches of multiple-family intervention. Leff et al. (1989) in the UK also demonstrated that there were no significant improvements in symptomatic relapse and level of expressed emotion in both the family psychoeducation group using the psychodynamic model and the supportive group intervention over two years.

Therefore, studies conducted in the UK and USA over the past two decades demonstrate that multiple-family group interventions for people with schizophrenia using psychoeducational, behavioural or other approaches indicate consistent positive effects on patients' relapse, for up to four years. Most of these group programmes included patients in the group meetings and consisted of an educational component and behavioural and problem solving skills training. However, some limitations of studies on MFG have been raised for future research. First, most research examined the effects of MFG on the patients' health condition, but less than half of the studies of MFG reviewed assessed families' health outcomes such as family burden, stress and psychosocial functioning. Those few studies of MFG, which have assessed the family-related outcomes, have shown inconsistent findings or have failed to find marked improvements

in family functioning or psychological well being. Second, education and medication are necessary but not sufficient alone for improving patients' physical and psychosocial health conditions, other potential therapeutic components of group intervention should be explored for achieving better patient and/or family-related psychosocial outcomes. As suggested by McFarlane (2002) who concluded from the findings of clinical trials of MFGs in the US in the 1990s, that expansion of social network occurring in a long-term multiple-family group (meeting for at least six months) results in an increase of available social support, which may be a potentially important influence on treatment outcomes. The importance of social support for families of people with chronic physical and mental illnesses has been well studied; and shown to be essential in contributing to psychological stability and a sense of social acceptance, and is thus associated with successful community tenure of patients with schizophrenia and other mental illnesses (Becker et al., 1998).

2.5.4 Evidence on effectiveness of family education and consultation

Although brief family education programmes for people with schizophrenia have been increasingly used in routine clinical practice because they are simple, short-term and feasible to implement, research on these interventions is limited (Solomon, 1996; Luckstead & Dixon, 1999). A review of literature on family education for people with severe mental illness by Solomon (1996) indicated that educational interventions of more than one session are effective to improve families' knowledge of the illness and their burden and stress in caregiving. However, there are only a few studies which evaluate the effectiveness of this approach of family intervention, thus limited evidence that these programmes reduce patient relapse can be found. Among the few controlled trials identified, Solomon et al. (1996, 1997) studied two brief family education programmes (a three-month individual consultation and a family education group programme) for people with serious mental illness in the US, and demonstrated that family education group intervention is more effective in improving families' self-efficacy in caregiving and patients' attitudes towards medication compliance immediately after intervention, when compared with family consultation and standard care. These effects on self-efficacy and attitude towards medication compliance were maintained over a six-month follow-up.

However, the two family education programmes did not show any significant effect on patients' re-hospitalisation.

For family consultation or supportive counselling, families who participate in this intervention may also attend educational groups or other family interventions simultaneously (Solomon, 2000). A survey by Lafuze et al. (1997) in Indiana, USA of 197 family members of mentally ill adults about their preferences for family educational programmes indicated that family members throughout the state have consistent needs and clear preferences for educational programmes. The most preferred format of family intervention is phone consultation with a professional to provide advice on managing patients' problems. Limited research has been conducted on this approach of family intervention and a few studies have integrated family consultation into a family psychoeducation programme for patients with schizophrenia in mainland China (Mingyuan et al., 1993; Xiong et al., 1994; Zhang et al., 1994). As mentioned above, Solomon et al. (1996, 1997) reported that the three-month family consultation programme showed greater significant improvement in self-efficacy in caregiving immediately after intervention than the standard care group. However, the family education group indicated relatively greater effects in both self-efficacy in caregiving and attitudes towards medication compliance than the family consultation and standard care. There were no significant effects of the two family interventions on other family-related outcomes including burden, stress and grief, and patient's re-hospitalisation.

In addition, family consultation is a short-term intervention for family members of people with severe mental illness who refuse or resist treatment. This intervention is focused on only one or two aspects of family psychosocial needs, consisting mainly of knowledge about the illness and advice on patients' behavioural management and coping with the illness. As there is very limited evidence for this intervention on patients and families' psychosocial conditions, further research is needed to support its use.

Summary

The past decade has witnessed the rapid growth of a variety of approaches to family intervention for people with schizophrenia in Western countries, which have been largely influenced by behavioural and cognitive therapies such as psycho-education delivered to family groups (McFarlane et al., 1995, Solomon et al., 1996). For the four modes

of family intervention (i.e. behavioural management, psychoeducation, multiple-family group, and family education and consultation programmes), most offer information and psychological support to family members, and some include the patient, although the theoretical orientation of these interventions varies considerably. Studies using these modes of intervention have produced inconsistent or inconclusive effects on patients, other than delaying relapse and improving drug compliance (Pharoah *et al.* 2001). Therefore, the widely-held belief of family researchers and clinicians that effective family intervention consists of a clearly-defined set of psycho-educational, cognitive and/or behavioural techniques following a step-by-step skill building format is unwarranted (Barbato and D'Avanzo, 2000). Such inconsistent evidence on commonly used approaches to family intervention in schizophrenia has aroused increasing interest among mental health professionals in exploring other modalities of family intervention and examining their effectiveness.

2.5.5 Studies of family intervention for people with schizophrenia and their methodological limitations

In spite of inconsistent findings from studies of family intervention for schizophrenia, the superiority of family intervention over routine outpatient care has been demonstrated and some significant effects such as relapse rate and medication compliance have been maintained for as long as two years. Recent reviews of more than 20 clinical trials of family intervention for people with schizophrenia conducted in Western countries and mainland China (Barbato & D'Avanzo, 2000; Dixon et al., 2000; Solomon, 2000; Pharoah et al., 2001) highlight questions about the effectiveness of family interventions which remain unanswered and require further research. First, there is a lack of conclusive evidence about the effects of commonly used models of family intervention on health outcomes of family carers of people with schizophrenia. With much responsibility and burden put onto family members caring for their relative with schizophrenia under the trend of community care, more preparation of family carers in terms of knowledge and skills of caregiving as well as coping with the illness and problems in caregiving should be provided within the family intervention programme. The family carers' psychosocial health conditions, which are significantly associated with

the care of their ill relatives and the treatment outcomes, should be emphasised and treated as important indicators for the effectiveness of a family-focused intervention. Systematic assessment of family-related outcomes of family intervention including family functioning and burden, perceived social support, and health services utilisation is demonstrated in this PhD thesis. In addition, as suggested by Pharoah et al. (2002), clinically significant changes in family outcome measures following the intervention were defined and examined in this thesis to understand the significant and meaningful changes in psychosocial health conditions of family caregivers in the direction of functionality, resulting from participation in the specifically designed family group work.

Second, little is known about the therapeutic value of different family intervention components or strategies. The described curative factors and mechanisms of change in the literature consist mainly of subjective accounts by therapists or facilitators of what they believed to be the important factors experienced within their own practice. Major identified factors include learning by analogy and identification of similar experience (Steinglass, 1998; Bishop et al., 2002), establishing a community of shared experiences (Steinglass, 1998), overcoming social stigma to the illness (Asen, 2002), and creating hope and adaptive patterns of coping and perspectives on illness and family life (Bishop et al., 2002). Although education about the illness and provision of social support are consistent ingredients of most models of family intervention for schizophrenia, they do not show any significant effect in isolation. Therefore, it is important to test the effect of family education and social support components in a specific model of family intervention emphasising their use, for example the mutual support group tested in this PhD study. In fact, mutual support groups have been used increasingly with patients with chronic physical diseases, terminal illnesses and enduring mental illness and there is convincing evidence that they can meet caregivers' psychosocial needs (Cook et al., 1999). Further research is also needed to explore the most beneficial and important components of the family intervention used. The exploration of caregivers' perceived benefits and important therapeutic components of the intervention is also one major purpose of the evaluation study of a family mutual support group in this PhD thesis. With better understanding of these crucial therapeutic elements within the family intervention,

it may be possible to develop a more consistent, reliable and effective family intervention programme for patients with schizophrenia.

Third, previous studies examined the effects of the highly structured family psychoeducation model such as Anderson et al.'s (1986) family psychoeducation programme and the manual driven behavioural model such as Falloon's (1985) family behavioural management programme. These studies indicated that these prevalent approaches of family intervention for people with schizophrenia did not show consistent immediate or long-term improvements in family members' psychosocial health conditions, when compared with routine care or other simple supportive interventions such as brief crisis-oriented family psychoeducation (Leff, 1994; Linszen et al., 1996) and supportive family education programmes (Bellack et al., 2000). Sellwood et al. (2001) also highlighted that effective family intervention may not require a specific defined set of advanced techniques, delivered through a highly structured model and manual of intervention, or with an intensively trained professional. The positive results of their trial of a needs-based family intervention indicate that family intervention should be designed from a family carers' perspective to be more able to recognise and meet their own psychosocial health needs in relation to caregiving, thus showing more positive family-related outcomes. With much increasing empirical evidence on multiple-family group interventions, bringing families together in supportive group intervention can produce specific and beneficial effects to family caregivers on improving their social support and coping with their caregiving role. The burden of care in schizophrenia is an issue that requires recognition, and attempts to ameliorate it, rather than to provide support, may be misplaced (Pilling et al., 2002).

Fourth, the implementation of family intervention techniques in routine practice has been hindered, however, for several reasons. Most importantly inadequate staff training and supervision, scarce resources, and lack of availability of trained staff, and difficulty in maintaining the effectiveness of an intervention delivered over many years compared to a relatively short term intervention which is subject to evaluation. Fadden (1997) shows great concern about implementation of family interventions in routine clinical practice and suggests that many of the difficulties experienced most frequently by trained staff are related to service issues. For cognitive-behavioural family intervention to

be effective, staff who are acting as therapists must be intensively trained and supervised in practice. It is often reported that trained staff cannot use the skills learned in their practice or intervention programme following training, without adequate supervision or management support (Kavanagh et al., 1993; Brooker, 2001). Also, therapists need to be able to work flexible hours in order to accommodate evening or weekend appointments. Those therapists who were able to visit families frequently reported that they only managed to do so by working in their own time or working outside regular hours. Dyck et al. (2002) suggested that running family intervention programmes with multiple-family groups may be one way of overcoming these staff and resource limitations for individual family treatment.

Fifth, most of the studies of family intervention for people with schizophrenia were conducted in Western countries. The results of the evaluation of cross-cultural applicability of Falloon's behavioural management programme in a Spanish-speaking population by Telles et al. (1995) did not support the positive findings from previous studies on patients' relapse and symptom control when applied to a socio-cultural diverse population. This finding indicates that socio-cultural factors may influence caregivers' responses to different types of family intervention. Hence, modes of family intervention, which were originated in the West, should be tested in a variety of patient populations with different cultural backgrounds such as the Hong Kong Chinese patients in this PhD study, thus providing more evidence on their relative effectiveness across cultures.

Finally, Barbato and D'Avanzo (2000) in their review of 25 clinical trials on family intervention found that relapsed patients usually leave the trial and that trials too frequently fail to collect data on the period following relapses. This dropout or incomplete data collection is of particular concern for a long-term follow-up study. When designing this PhD study, a few strategies such as asking for preference and allowing more flexibility in time or convenience to attend the sessions of intervention and providing regular contact with and encouragement from the group facilitator and peer co-leader between group meetings, were built into the intervention in order to lower the attrition rate of the study.

2.6 SOCIO-CULTURAL AND PRACTICAL ISSUES RELEVANT TO THE USE OF A MULTIPLE-FAMILY GROUP INTERVENTION IN A CHINESE POPULATION

The majority of family intervention studies in schizophrenia have been undertaken within the USA and the UK, with the exception of a few studies from other European countries (Buchkremer et al., 1995; De Giacoma et al., 1997; Nugter et al., 1997) and only a couple in mainland China (Xiong et al., 1994; Zhang et al., 1994). This may limit the applicability and generalisation of findings of the studies to patients with schizophrenia from other cultures. The cross-cultural validity of family intervention strategies for schizophrenia had been raised in Telles et al.'s (1995) study, as mentioned in Sections 2.5.2 and 2.5.5, on the low-income Hispanic American families caring for a relative with schizophrenia. The most significant finding was that the behavioural family intervention tested in the study exacerbated symptoms for the patients classified as 'poorly acculturated' population and did not show significant improvement in family-related outcomes, when compared to routine psychiatric care. This finding raises an important question, which is whether socio-cultural factors of patients and their families may have a potentially important influence on the effectiveness of family intervention when applied in different cultures. This finding also underscores the need to modify intervention strategies to be culturally sensitive; otherwise, it may be received unfavourably with untoward outcomes (Penn & Mueser, 1996). According to Hsu (1995), successful psychological treatment should include careful consideration of the feasibility and acceptability of the participants with diverse cultural backgrounds. This, in turn, raises the question of what particular aspects of Chinese culture are likely to influence the effectiveness of any family intervention and also what implications these cultural factors have for the design and implementation of such interventions (Fung & Ma, 1997). It is to these questions that the discussion now turns. Although traditional beliefs, values and lifestyles of the Chinese families in Hong Kong have become intermixed with Western culture, family continues to be an important source of informal support for each family member; however, it becomes more difficult for a family to fulfil its role of primary caregiver for family members to the extent that it has in the past (Ng, Philips & Lee, 2002).

As well as a variety of techniques and formats for family interventions, the health professionals should take into account of the uniqueness of the Chinese culture in Hong Kong when applying family interventions, which were tested and commonly used in the West. The meaning of family relations and some behavioural constructs may differ from one culture to the other and whether the existing models of family intervention can be applied to the cultural context of the Chinese people is still questionable (Fung & Ma, 1997).

Traditional therapist-led single-family therapy that focuses on the psychological problems of the patient or family members may not be easily accepted by Chinese families because of their reluctance to reveal private thoughts and feelings in front of others, especially a therapist or someone not familiar to them. Open expression or discussion of feelings is generally not encouraged. Chinese people may often believe that excess emotion such as anger endangers health and, therefore, should be controlled (Meredith et al., 1994). Communication between family members and close relatives and friends is important in Chinese culture, however, taking a different form from Western cultures. Studies suggest that the Chinese are less likely to express affection to each other through words and touch, than people from Western countries. They tend to show their concern and feelings for each other through action, for example, by taking care of actual needs rather than communicating those feelings verbally (Hsu, 1995). Therefore, it may be difficult to build a rapport between the therapist and the family in the traditional family therapy session (Fung & Ma, 1997).

Tseng, Qin-Yun and Yin (1995) in their discussion about the value of psychotherapy for Chinese families suggested that Chinese families put much emphasis on interdependence, in contrast with the concept of independence in Western cultures, and so these families may be considered extremely cohesive. Family members depend on each other for support, both emotional and in carrying out daily tasks. As Chinese families place high value on maintaining collective obligation and harmonious interpersonal relationship, they generally do not confront each other or deal with the problems directly. Help from the extended family and friends are usually enlisted first without the knowledge of the other members involved. If that is ineffective, it is not uncommon for a mutually respected or trusted third person, such as an uncle or an older

person, to be brought in to mediate the dispute or conflicts (Hsu, 1995). Therefore, extra help outside the family sometimes may be useful in solving the family difficulties and problems.

Pearson and Ning (1997) reviewed the literature on family care of Chinese people with severe mental illness and found that a social group of families with similar experiences and situations in caring for a relative with schizophrenia may serve this purpose. Leung, Wong and Siu (1993) in their exploratory study of the effects of mutual support groups conducted in Hong Kong based on interviews with Chinese family participants, suggested that such groups are effective in offering practical advice and shared experiences, as well as providing appropriate responses to the unmet family needs.

On the other hand, the emphasis on collective uniformity and extreme cohesion in Chinese families may increase treatment compliance. Family caregivers can support and nurture their ill relatives through practical help and concern over their health needs, especially the physical needs (Meredith et al., 1994). Leung, Chien and Mackenzie (2000) studied on health needs of Chinese families caring for a critically ill relative and reported that a healthy family is also adaptable, having the ability to change its role relationship and family environment and rules in response to changing circumstances and situational or developmental stress, such as one family member with long-term or critical illness. Caudle (1993) suggested that the Latin American culture also places particular emphasis on valuing caring behaviour within families; these families have been found to be the main source of support for both physical and emotional needs of family members with severe illness. Nevertheless, for Chinese families any attempt to intervene to enhance the independence of the patient will be made with considerable respect to the traditional protective and dominant roles of the elders and parents who are often the primary caregivers.

In addition to the unique pattern of communication and relationship, the emphasis of hierarchical power and parental authority may also create obstacles to family interventions. The distribution of power is based on generation and age (Meredith et al., 1994). In this traditional family system, the eldest person of the top generation usually has the ultimate power to make final decisions regarding important matters in the family. Hsu (1995) in her study of mental health issues in Chinese families suggested that the

younger generations are not expected to question or challenge the decisions of their elders, which appear to run contrary the purpose of family intervention in promoting collaboration through mutual concern and discussion. This typical strong parental power in Chinese families may produce resentment and un-cooperation from the elder family member, who would perceive the younger group members or the therapist as a threat to their authority (Fung & Ma, 1997). It is therefore important to take into account the Chinese culture when establishing a helping relationship in family interventions, for example, emphasis on mutual respect and equal position, but not to be rigidly confined to the passive reception of teaching and information by the families.

The particular characteristics of Chinese culture outlined above suggests that family interventions need to be flexible in providing information, skills and techniques about caring for people with schizophrenia, and responding to family members as needs arise. In view of the general lack of knowledge and misconceptions about mental illness for the general population in Hong Kong, interventions are more likely to be more effective if they put more emphasis on the provision of knowledge about schizophrenia, using simple language that can be understood by the families who are often from the lower social class (Castle Peak Hospital, 1999), than on abstract theoretical concepts of schizophrenia. Concrete guidelines for stress reduction, management of patient's symptoms and behaviour, and effective problem solving skills through different phases of illness can be included and rehearsed (Leff, 1994; Fung & Ma, 1997).

In fact, the family hierarchy and unique pattern of Chinese family communication may have great impact on the family process, interactions and functioning (Chen & Davenport, 2005), which in turn can influence the family lives and health conditions, as well as the care provided to the relative with schizophrenia. This further reinforces the previous findings on the effect of dysfunctional family processes and communication on the course of illness in schizophrenia, and may explain why there are still many studies concentrating on this issue. This highlights the importance of examining what type of family intervention is appropriate and effective for Chinese families of people with schizophrenia and the ingredients of the intervention that are perceived to be helpful to them, thus being the sources of therapeutic outcomes.

Chou, Liu and Chu (2002) concluded from their quasi-experimental study on the effects of a family support group for 70 patients with schizophrenia in Taiwan, that family intervention is well received by Chinese family caregivers not because of what they learn from the expertise of health professionals, but rather because they feel that the professionals finally listen to them and understand their own experiences of caregiving. A feeling of universality with other members of the group about their problems in caregiving, as identified in other therapeutic groups by Yalom (1998), was found to be a very important element for the families in the study, because they felt comfortable in receiving help from other families with similar problems and, at the same time, they felt competent in giving help to them. These findings provide a portrait of a flexible, supportive, client-directed approach to family intervention for Chinese families, which may be acceptable in Chinese culture and enable caregivers to cope with their caregiving role and enhance their competence in handling situations of caregiving, thus improving the consequences for their family life (Chou et al., 1999). Therefore, the feasibility and applicability of this mode of intervention for Chinese families of patients with schizophrenia was also tested and reported in this PhD thesis.

2.7 EMERGENCE OF THE MUTUAL SUPPORT GROUP AS AN INTERVENTION FOR FAMILY CARERS

2.7.1 Mutual support groups for patients with chronic illness

The proliferation of family mutual support groups in the United States and other Western countries in the 1980s is part of the larger social movement of self-help and mutual aid organisations for people affected by a variety of chronic diseases and stressful life circumstances, whose needs have been inadequately addressed by traditional health care interventions (Hatfield & Lefley, 1987; Heller, Roccoforte & Cook, 1997). Increasing research evidence indicated that participation in mutual support group for patients with different chronic physical and psychological problems such as diabetic mellitus, bereavement and traumatic experiences, cancer and other terminal illnesses, and chronic mental illnesses was highly associated with improvements in psychological adjustments of these patients (Spiegel et al., 1989; Zola, 1991), as well as the family members (McCallion & Toseland, 1995). This growth in mutual support groups for

patients led to an increasing interest in extending their use and examination of its value for family care of people with chronic physical and mental illnesses during the 1990s (Cook & Wright, 1996).

Kurtz (1997) reviewed the literature in the 1980s and 1990s on mutual support groups for different types of patients with chronic illness and indicated that, given the wide range of composition and individual group ideals, there are almost as many definitions and classifications as there are groups. Despite different definitions and functions of mutual support groups, Kurtz suggested that mutual support is considered as a process of sharing common experiences and situations of people within a group, who learn from one another how to cope with their own problems. A mutual support group can be defined as "a type of mutual helping unit that comprises a group of people and a facilitator to share and deal with some common needs" (Nichols & Jenkinson, 1991, p.11), and thus is a voluntarily participating structure for reciprocal support to satisfy common needs and bringing out desired social and personal changes (Oka, 2003).

One influential and widely held definition given by Katz et al. (1992) highlights eight important attributes, which define a mutual support group. These are: (a) an acknowledged purpose in coming together, more than mere social interaction; (b) voluntary participation with eagerness to regain normal life; (c) face-to-face small group structure, usually between three to 12; (d) active personal participation in discussion and other group activities; (e) starting from powerlessness, thus, learning to regain control; (f) help giving and receiving – everybody relying upon other members' efforts, skills, knowledge, and concerns as its primary source of help; and (g) sharing common life experiences and problems.

When applied to health care intervention, mutual support groups often are characterised as a client-led social or community alternative to the professional-controlled medical programmes that dominate the mental health system today. According to the functional models of self-help groups prevalent in the USA during the 1980s, the inner-focused, therapeutic and supportive groups of patients with chronic physical diseases tend to accept the norms and values of society and focus on providing self-fulfilment and personal growth opportunities that promote individual change through empowerment and consciousness-raising goals, such as more initiative in improvement of

knowledge and skills regarding their own self care and in seeking community support services (Norton, Wandersman & Goldman, 1993). Studies of mutual support groups for patients with chronic medical illnesses (Lorig et al., 2000), particularly those with diabetic mellitus (Gleeson-Kreig, Bernal & Woolley, 2002), show evidence that many of these patients are expert in managing their own disease, and this can also be used to encourage other fellow patients to become 'key decision makers' in their treatment process. Gleeson-Kreig et al. (2002) also emphasised that some of these 'expert' patients can contribute their self-management skills in the support group for other patients with short duration of illness and provide insights for further improvement of the intervention or community services.

As recommended by the Department of Health, UK (2001) on the new approach to chronic disease management in the 21st century, more than just patient education is necessary to improve treatment compliance among patients with chronic illness; instead the introduction of user-led mutual support group interventions for people with chronic illness should be highly valued and facilitated by health care professionals. The group members promote mutual peer help, rather than traditional types of psychological therapies involving hierarchical therapist-client relationships or therapist-directed sessions. On the other hand, these mutual support groups allow professionals to performing auxiliary, facilitative or advisory roles as part of the treatment process (Reissman, 1995).

2.7.2 Mutual support groups for families of peoples with chronic and severe mental illness

In the 1980s, multiple-family group intervention was increasingly used among families of people with chronic and severe mental illness. Most of the clinical trials on family intervention for people with chronic and severe mental illness in the USA and UK were professional-led, didactic education programmes, with patient participation, and focused on teaching family members how to take care of their patient at home and to prevent patient's relapse (McFarlane, 2002). The use of mutual support groups as an approach to family intervention for these patients was not commonly accepted and used in Western countries until the late 1980s (Lefley, 1996). With increased attention and

concerns about the health needs of family caregivers under the trend of family-based treatment for severe mental illness, many clinicians and researchers suggest that family intervention should not only contribute to patient recovery but also meet the families' psychosocial needs in caregiving (Solomon, 2000). Mutual support groups for family caregivers of a relative with severe mental illness, which provide information about mental illness, its treatment and community resources, opportunities to share feelings and experiences without fear of stigma, and emotional support and empathy, has been increasingly established throughout the US, such as the National Alliance for the Mentally Ill in the early 1990s (Burland, 1998), purporting to meet the needs for social support and other aspects of mental health of these families.

Recent studies indicate significant positive effects of the use of mutual support groups for family-based treatment of patients with chronic mental health problems such as eating disorders, dementia and alcoholic abuse, on some family-related outcomes (Colahan & Robinson, 2002; Doyle et al., 2003; McCallion & Toseland, 1995). Toseland and Rossiter (1989) reviewed 10 experimental or quasi-experimental studies on caregivers of patients with dementia in the 1980s and showed that mutual support group can produce significant positive effects on families' psychosocial outcomes such as burden and distress, and coping with caregiving and social isolation, when compared with routine care. Colahan and Robinson (2002) in their study of family support groups conducted within an eating disorder service centre of a London NHS hospital reported that family members are able to gain insight into their young relative's eating problem, improve family communication and, in presenting their experiences from the position of being in a similar predicament, provide support to participants in order to alleviate their sense of isolation and resistance to treatment. Despite the use of mutual support groups expanding into the domain of chronic mental illness, the positive values of this intervention to patients and their families are not conclusive (Heller et al., 1997).

While there are few clinical trials on mutual support group for families of patients with schizophrenia in Chinese and Western countries, the literature is replete with case studies, cross-sectional surveys and qualitative and quasi-experimental approaches of single treatment group, emphasising the apparent benefits of the group in maintaining the psychological and social well-being of families (Ma, 1992; Heller et al., 1997). However,

there is relatively little empirical evidence, which supports any enthusiastic claims of their benefits in improving families' functioning and satisfying their health needs (Pearson & Ning, 1997). Studies of mutual support groups for families of people with schizophrenia and other severe mental illnesses are reviewed in Chapter 3.

The paucity of empirical studies on mutual support groups for families of adult people with schizophrenia over the past two decades may be explained by the following: (a) the families tend to be socially isolated by the demands, burden and stigma of the illness, and their feeling of guilt and self blame for the illness; thus, they seldom seek help from professionals and other people outside family (Cole & Reiss, 1993); (b) support groups are informal network of individuals depending on the leadership of peer volunteers, and challenges like maintaining momentum, ensuring regular evaluation and addressing individual and group changes are accentuated even more than in professional-led programmes (Katz, 1997); (c) the goals, structure and activities of mutual support groups for these families vary as widely as the communities where groups are present, thus it is difficult to replicate a standardised procedure of intervention and investigate its effectiveness and applicability in different settings and across cultures.

However, families caring for a relative with schizophrenia usually experience negative reactions from society towards patients and themselves, and many isolate themselves from their natural helping network due to feelings of shame and stigma. Mutual support tends to be viewed as a replacement support network for those in psychosocial crisis, one that, by its nature, is more appropriately able to provide empathy and support for participants who are 'in the same boat' (Gidron, Guterman & Hartman, 1990). This PhD study attempted to overcome some of the difficulties in design of a structured mutual support group programme and tested its effectiveness in a group of Chinese families of people with schizophrenia in Hong Kong.

All mutual support groups function as informal social support systems in that they promote an enduring pattern of continuous or intermittent ties that play a significant part in maintaining the psychiatric and physical health over time. Social support theories broadly hold that social support and social networks are useful to promote mental health because they: (a) buffer the impact of stressful life events; and (b) directly influence or reduce the occurrence of various mental disorders (Champion & Goodall, 1994; Lakey &

Cohen, 2000). Studies demonstrate the influence of life events on the occurrence of various psychiatric and physical disorders, and which appears to be mediated by adequate perceived social support (Champion, 1990; Chou et al., 1999). Cohen and Wills (1985) in their reviews of studies on families of mentally ill people, conclude that emotional and instrumental support from intimate social interactions can have a potential buffering effect on the impact of stressful events in caregiving. The theoretical backgrounds of social support and mutual support groups are presented with details in Chapter 3.

2.8 CONCLUSION

In spite of the rapid developments in pharmacological and psychosocial treatment of schizophrenia, the dissemination of psychosocial interventions as usual practice within mental health services has been slow and patchy across Western and non-Western countries (Penn & Mueser, 1996). Families, particularly those family members who live with their relative with schizophrenia, often face and report a high level of psychological distress, social stigma, emotional frustration such as guilt and loneliness, and practical problems in living with and/or taking care of the patient at home. Several types of family-focused intervention such as family psychoeducation and behavioural family management programmes have been developed and found to be effective in meeting the needs of families in caring for a relative with schizophrenia. Recent reviews of clinical trials on family intervention in Western countries indicate that among these modes of family intervention, the psychoeducational and supportive group programmes are more effective in reducing patients' relapse and improving medication compliance up to two years' follow-up, than the usual psychiatric care. However, there are important shortcomings of studies on family intervention and limitations in our understanding of its effects for patients with schizophrenia and their families. These include:

(a) Studies of the effects of these commonly used modalities of family intervention on patient and family-related psychosocial outcomes, other than patients' relapse and medication compliance, are inconclusive.

(b) Implementation of family intervention techniques in routine practice has been hindered due mainly to inadequate staff training and supervision, scarce resources, or lack of availability of trained staff. Moreover, it may be difficult to maintain the

potency of an intervention delivered over many years compared to a relatively short-term intervention, which is subject to evaluation.

(c) The great majority of family intervention studies in schizophrenia have been undertaken in Western developed countries. There have been only two studies in mainland China. Findings of Western studies cannot be easily generalised to non-Western populations because family interventions probably need to be adapted to meet cultural requirements if they are to be optimally effective

(d) Little is known about the therapeutic components or mechanisms of these family psychosocial interventions, through which they produce their effects.

However, there is evidence that the mutual support group is effective in some chronic physical and mental illnesses. There is preliminary evidence from descriptive studies among people with schizophrenia in Western and non-Western people and, thus, this approach of family intervention needs to be empirically evaluated to establish its effectiveness with families of persons with schizophrenia.

Mutual support group programmes require only limited training for nurses or other health professionals to serve as facilitators and provide a flexible, interactive client-directed approach to help families cope with their caregiving role. Thus, the mutual support group may be an effective alternative model of family intervention for schizophrenia. It is also important to test this intervention among Chinese families who are living in a specific culture characterised by a strong sense of filial responsibility, close interdependence, and mutual support. This doctoral study builds upon preliminary evidence for the effectiveness of mutual support groups for Chinese families and takes account, in its design, of the methodological limitations of previous studies on family intervention discussed in this chapter. Thus the aim of this doctoral study, using a randomised controlled trial design, was to implement and evaluate a mutual support group for helping Chinese family carers of people with schizophrenia in Hong Kong.

CHAPTER 3 MUTUAL SUPPORT GROUP INTERVENTION FOR FAMILIES OF PEOPLE WITH SCHIZOPHRENIA AND OTHER SEVERE MENTAL ILLNESS

3.1 INTRODUCTION

Chapter 2 described the cultural and practical issues that are pertinent to the use of a multiple-family group intervention in the Chinese population and the emergence of mutual support group interventions for family carers in severe mental illnesses were also outlined. This chapter starts by providing the theoretical concepts of social support (in Section 3.2) and its health benefits to family members caring for a relative with mental illness (in Section 3.3). The chapter then describes the conceptual basis of mutual support groups and their potential benefits in mental health and intervention for people with mental health problems (Sections 3.4). It then reviews literature from a systematic search to assess the effectiveness of mutual support groups for helping family carers of people with schizophrenia and other severe mental illness (Section 3.5). The search strategy for this review is described in Section 3.5.1. With the benefit of this review, the chapter highlights what is known about the effects and active ingredients of mutual support groups, and unanswered questions (Section 3.6).

This chapter also provides a rationale for the evaluation design used in the study described in this thesis (Section 3.7). The chapter concludes with a rationale for the present PhD study, which examines the effects of a mutual support group in a sample of Chinese family carers of outpatients with schizophrenia and identifies the therapeutic mechanisms of the intervention.

3.2 THE CONCEPT OF SOCIAL SUPPORT

In the past two decades, there have been a large number of studies by social psychologists and health professionals on the characteristics of the social environment and its relationship to the health condition of patients with different types of acute and chronic illnesses and the implications for health promotion to these patients and families (Billings & Moos, 1985; Peirce et al., 1996; Cohen, 2004). Different types of support that patients received from others (Cohen, Bottlieb & Underwood, 2000), the quality and quantity of social interactions and support (Brissette, Cohen & Seeman, 2000), the structure of social network (Berkman & Glass, 2000), and the feelings of belongingness versus loneliness and isolation (Cacioppo et al., 2002), have been

reported as predictors of patients' health as well as family carers' well being. However, there is increasing evidence that different characteristics of social relationships and social environment influence mental health through different and independent underlying mechanisms and the literature on the effects of these characteristics on health highlights only a few constructs, including social support, social network and integration and negative social interactions (Wills & Fegan, 2001). Lakey and Cohen's (2000) guidelines of social support measurement and intervention suggest that it is only by understanding the characteristics and functions of social environment and social relationships that influence people's health, that health professionals can successfully apply this knowledge to health promoting interventions to patients and their family carers as needed, particularly those with chronic illness.

3.3 THE HEALTH BENEFITS OF SOCIAL SUPPORT TO FAMILY CARERS OF PATIENTS WITH SCHIZOPHRENIA AND OTHER SEVERE MENTAL ILLNESS

Social support can be operationally defined as the psychological and material resources and social interactions provided by others in the family carers' social network that may help to improve their ability to cope with the mental illness. However, the adequacy of social support should be measured from the perspective of patients or family carers because social interactions regarded as supportive by the deliverer may not always be so perceived by the recipient (Coriell & Cohen, 1995). Under this definition, however, studies on the amount of social support provided to the family carers often measures three aspects: the number of people providing support to the family carer, the amount of effective psychological or material resources available to the family carer, irrespective of the absolute number of people providing support, and the level of satisfaction experienced by the family carer for the support provided by relatives, friends and other closely related people (Lakey & Cohen, 2000; Wills & Fegan, 2001). Wills and Fegan (2001) looked at the importance of social support in relation to health promotion and reported that many studies have measured more than one of these three aspects, in order to obtain more useful and adequate information of social support.

Literature on the concepts of social support has placed much emphasis on the functional dimensions in terms of three types of resources: instrumental, informational and emotional support (Bogat, Sullivan & Grober, 1993). Instrumental support

involves the provision of material aids, for example, financial assistance and practical help with daily tasks. Informational support refers to the provision of relevant and appropriate information intended to help a person cope with current difficulties, and typically takes the form of advice or guidance in dealing with one's problems. Emotional support involves the expression of empathy, caring and trust and provides opportunities for emotional expression. This type of support can only be found between people such as family members, with intimate and long-standing relationships. A few studies also suggest other functions of social support such as maintenance of identity, providing access to social contacts and companionship for various kinds of daily activities (Pierce et al., 1996). Such typologies of social support provide a basis for determining whether the effectiveness of different kinds of support differs by the nature of stressful events, or by the characteristics of the family carer or patient suffering adversity. In addition, measurement of these functional dimensions is based on the assumption that it is the quality of available resources that is most important, thus, the measurement aims to assess the extent to which supportive functions are available to a person (Cohen et al., 2000). Therefore the results of these measurements can provide us with information about the availability of a particular type of support if needed, for example ability to confide in somebody about problems and concerns; but do not necessarily determine who the support comes from.

3.3.1 Social support as a buffer to psychosocial stress

Studies on factors influencing social relationships of family carers of patients with chronic and severe mental illness indicate that frequent and prolonged patient hospitalisations, persistent severe psychiatric symptoms of the patient and social stigma of mental illness can contribute to the social isolation of both the patients and their family carers (Fisher & Tessler, 1986; Horwitz & Reinhard, 1992; Lefley, 1996). The number of people in the family support network may diminish as individual carers burn out under the chronic strain of caring or become isolated from people in their social network mainly due to the negative effect of stigmatisation of mental illness (Lefley, 1996). Social support can promote the health of these family carers through the mechanisms of stress buffering. The stress buffering model asserts that social relationships and connections can eliminate or reduce the effects of stressful caregiving experiences by providing the psychological and material resources needed

to cope with the difficulties arising from caregiving and looking at adverse experiences in a more positive light (Cohen, 2004).

Recent literature also suggests that the critical factor in social support operating as a stress buffer is the perception or belief that others will provide appropriate aid, which may bolster one's perceived ability to cope with demands, thus changing the appraisal of the situation to be more positive and hopeful and improving the psychological and maladaptive behavioural responses such as depression and social withdrawal (Cohen, 2004; Lakey & Cohen, 2000; Tausig, Fisher & Tessler, 1992). The stress moderation effects of perceived social support to families caring for a patient with schizophrenia and other severe mental illnesses are emphasised in the model, mainly: dealing with stressful experiences of social stigma, reducing social isolation due to constraints from caregiving and guilty feelings due to having a relative with schizophrenia, and enhancing emotional support and psychological ventilation of distress and burden in caregiving (Bernheim & Lehman, 1985; Turnbull, Galinsky, Wilner & Meglin, 1994).

In addition, the receipt of actual or practical support to reduce difficulties in caregiving can also play a role in stress buffering. Social support may alleviate the impact of stress by identifying alternative ways of solving a caregiving problem through discussion, by providing practical help to solve the problem, by reducing the perceived importance of the problem, or by providing a distraction from the problem (Cohen et al., 2000; Wituk et al., 2000). Constructive advice provided by supporting people, as well as social companionship, can also facilitate healthy behaviour such as exercise, personal hygiene, recreation, and rest (Cohen, 2004).

The family system is often considered to be an open system and part of the larger social group and community. Family mal-adaptation to the demands of care for a family member with chronic and severe mental illness can create major hardships for the family system and may result in family disruption, disorganisation and crisis (McCubbin & McCubbin, 1993). Families of patients with schizophrenia who have already encountered a wide range of day-to-day problems affecting various aspects of their lives may find that this has a significant impact on the entire family system. Successful family adaptation to the mental illness requires the family to make adjustments to their usual roles and responsibilities within the family in order to meet the needs of individual family members as well as the family needs as a whole. Studies in the US and Chinese populations indicated that elders and parents of Asian and

Hispanic heritage expect their family members to participate in their care, especially when they are sick, whereas Caucasian families were more likely to view living with their children as a sign of failure (Kawachi & Berkman, 2001; McCubbin & McCubbin, 1993). As the cultural landscape of Hong Kong blends with Western cultures, Hong Kong Chinese may expect a mix of family care and attention and community services when a family member suffers from a chronic illness. Many of the families in Hong Kong will be willing to take care of their family member with schizophrenia; but due to difficulties in their financial situation and accommodation, they need to spend time building relationships and making decisions about how to best care for the ill relatives by concentrating on building community support networks (Chan & Yu, 2004; Chien & Norman, 2003).

The psychological and social support available to family members and the community resources they can utilise to manage the internal and external strains as the result of the burden of care, help to protect the family unit from major disruptions and psychological distress during these times of hardship and change (Saunders, 1999; Stein & Wemmerus, 2001). Much evidence has indicated that families' health needs relating to the burden of care can often be met by providing adequate psychological and informational support related to caregiving (Gidron et al., 1990). On the other hand, a lack of such support from relatives, friends and health care professionals will increase the risk of family dysfunctions and reduce self-efficacy of the family in caring for the mentally ill relative (Chou, LaMontagne & Hepworth, 1999).

Moreover, family carers often cannot get adequate social support from health professionals who work in a pressured environment that allows little time to establish a working alliance with families, or to develop treatment goals (Turnbull et al., 1994); They may also not empathise with the families' needs and to a certain extent may believe that the family is a dysfunctional and pathogenic cause of the illness, a stance that not only increases guilt and defensiveness of the families but also makes a working alliance difficult to establish (Saunders, 1999). Whereas a mutual support group has the advantage of responding to the needs of these families in availing themselves of social support from others with similar situations and health needs in relation to caregiving.

3.3.2 Social support and the health benefits of social integration

Social integration is operationally conceptualised as the totality of the range of social ties within a family carer's social environment, rather than a particular social relationship with significant others. It is a multidimensional construct (Brissette et al., 2000), which includes a behavioural component (that is, level of engagement in a wide range of social activities or relationships) and a cognitive component (that is, a sense of communality and identification with one's social roles). The concept of social integration was identified by Durkheim's (1951) sociological study on relationships between social conditions, social ties of people in different social strata and risk of suicide. One of his important findings concerning social integration was that stable social structure and satisfactory social identification, particularly found in those of a higher social class and living in urban areas, are protective to people's psychological problems such as depression and serve to regulate their social involvement and behaviour such as suicide (Cohen et al., 2000).

The main effect model (Cohen, 1988) argues that social integration is beneficial to people irrespective of whether they are under stress (for example, demands in caregiving). People who live in a social network are subject to social controls and peer pressure that influence their normative health behaviour; for example, their peer group may influence their lifestyle - whether they exercise regularly, eat a healthy diet, or take illicit drugs. Social integration is thought to engender feelings of responsibility for others resulting in positive self-worth and increased motivation to take care of oneself so that responsibility can be fulfilled. Concepts of social role and responsibility that are shared among a group of people help to guide social interaction by providing a common set of expectations about how people should act in different roles. Interacting with others is also evidenced to aid in emotional regulation such as increasing the person's positive outlook and helping him/her limit the intensity and duration of negative emotional states such as anxiety and depression (Cacioppo et al., 2002; Cunningham et al., 1998), resulting in suppressed neuro-endocrine response and enhanced immune function (Cohen, 1988).

These concepts of social integration can be applied to family caregiving for chronic and severe mental illness. Studies of long-term caregiving to a relative with severe mental illness conducted in Western countries indicates that family carers sometimes become increasingly psychologically distressed over time and that efforts to cope with the chronic strains and demands of care can significantly change the

structure and composition of carers' support networks (Biegel et al., 2000; Lefley, 1996). Many carers may become socially isolated from other people in their social environment and thus worsen their mental health and functioning. Wright (1998) summarised the data from the Indianapolis Network Mental Health Study in the US, which is an exploratory longitudinal study of the social networks of 116 people recently diagnosed with severe mental illness, and found that providing these family carers with more social ties and connectedness with people, particularly other family carers in a similar situation and with better understanding of their problems in caregiving, is evidenced to increase their enthusiasm to improve their psychological and social functioning, thus they can better cope with the strains and demands of long-term caregiving to their ill relative. Having a wide range of social network ties also provides multiple sources of information that may influence health-related behaviour of the family carers, resulting in more effective use of available health services, or helping them to avoid stressful situations. Mutual support groups for family carers of patients with chronic physical and mental illness, which aim at increasing social connectedness between the participants with similar situations in caregiving, are presumed to serve these health promoting purposes.

Social integration is found to be a precursor to several determinants of mental health – some of them are positive such as sense of belonging and perceived social support and some are negative such as chronic strains and high levels of criticisms within social contacts and relationships (Magliano et al., 2002; Pearson, 1990). A longitudinal, exploratory study by Berbrier and Schulte (2000) on the effects of social ties on the mental health of families of people with chronic mental illness in the US suggested that social integration can produce benefits to an individual known as the relational rewards, including a sense of belongingness and social identity, a source of self-esteem, and a sense of mastery of own life situation.

While people often experience rewards from these social relationships, they also often entail obligations and stresses in caregiving that cannot be avoided. Chronic strains arising in family roles in caring for a relative with schizophrenia or other severe mental illnesses have long been noted to have such negative effects upon well-being, and to increase psychological distress (Kouzis, Ford & Eaton, 2000). Whether the obligations arise for moral, cultural, or financial reasons, binding integration captures the nature of family relationships: these social ties inherently involve an extensive commitment of time and energy that is not easily averted; and these relationships seem

likely to be associated with relational costs (Ensel & Lin, 1991). This is particularly true when one family member has had chronic and severe mental illness, requiring a long period of care provided by other family members. For Chinese families the cultural specificity indicates that the collectivist ethic, strong filial responsibility and interdependent relationships, might contrast greatlywith the individualism of people in modern Western societies (Yang & Pearson, 2002), exacerbating this relational cost.

However, non-binding integration, which refers to those relationships in which the carers engage more voluntarily such as membership of a social group (Berbrier & Schulte, 2000), may be beneficial to these carers. Given its voluntary nature, even though their relationships may be more "loose" or temporary than family relationships, it is possible these social relationships involve fewer relational costs than binding integration, and generate more relational rewards such as helping them to adjust to the long-term and complicated demands of caregiving (Wright, 1998). Berbrier and Schulte (2000) suggested that turning from family to non-family relationships for social support means changing from a pattern of commitment to one of increased flexibility. Participation of a mutual support group may be a means of establishing this non-binding integration from which they can receive some of these relational rewards. Wright's (1998) study on the social network context of caregiving in chronic and severe mental illness emphasised that efforts of mutual support groups can focus on reducing social isolation of both patients and their families and fostering of close emotional ties with not only closely related relatives but also people outside the family who are wiling to offer desired help and emotional support. The theoretical concepts relating to the mutual support group are presented in Section 3.4 and these concepts provide support to the use and evaluation of the intervention for families of patients with schizophrenia in this PhD study.

3.4 THE CONCEPTUAL BASIS OF MUTUAL SUPPORT GROUPS

The importance of mutual support to families of people with schizophrenia and other severe mental illnesses has emerged from the stress-vulnerability and coping model (Lazarus & Folkman, 1984), which assumes that family adaptation and ability to cope with the immediate stress of hospitalisation and ultimately with the ongoing stress in caring for a patient with mental illness, is determined by whether or not the illness and hospitalisation is perceived as a threat to well being or their caregiving to the ill relative is considered a very difficult task to be mastered. The important

moderating effect of social support to the family carers is emphasised in the model as: facing the stressful experiences of social stigma (Bernheim & Lehman, 1985), reducing social isolation due to constraints from caregiving and guilty feelings due to having a relative with schizophrenia (Turnbull et al., 1994), and enhancing emotional support and practical assistance in caregiving (Wituk et al., 2000). These therapeutic components can be found in a mutual support group for families caring for a relative with severe mental illness.

Apart from understanding the potential contributions of mutual support groups to family carers from the concepts of social support and social integration in Sections 3.2 and 3.3, there are some other commonly cited theoretical frameworks, in particular social relationships and empowerment, social comparison theory, principles of social learning, and cognitive theory, which can provide insightful and partial explanations of how the majority of mutual support groups work. These frameworks (discussed in Sections 3.4.1 to 3.4.4) can provide important information to guide the design and implementation of the mutual support group intervention to the family carers of patients with schizophrenia reported in this PhD thesis.

3.4.1 Fostering social relationships and empowerment

Social relationships have been found to be most helpful to people who have a small or loosely related social network and, thus, they are unable to obtain the help they need from people in the network. Important social relationships are the means by which the individual acquires a social identity and receives social, emotional and material support (Kurtz & Powell, 1987). As the natural networks cannot protect people such as those families caring for a relative with schizophrenia from stigmatisation and social isolation, new social relationships may be useful to uphold a different set of values and norms while simultaneously accepting people with similar problems (Borkman, 1999). Rappaport (1993) suggested that these shared beliefs and stories from a kind of group narrative that constitutes a social identity, distinguishing the support group form any kind of formal psychotherapy such as cognitive behavioural family group therapy. The mutual support group can be an important asset to develop such new relationships in an accepting social environment and especially important if the families have been isolated by their problems related to caregiving to patients with severe mental illness. It appears that mutual support groups provide an

informal, consistent parallel system of peer support to complement professional help and social support from relatives and friends (Wituk et al., 2000).

In viewing the mutual help processes within a support group for family carers, psychological empowerment at the individual level is purported to build on the supportive social context and by making connections with people outside the group. This is a social action process by which the family carers as group participants learn to gain mastery over issues of concern to them (i.e. perceptions of personal control), a proactive approach to life and a critical understanding of their intrapersonal, social and societal environment (Zimmerman, 1990). Maton and Salem (1995) have applied this idea in a case study of GROW (also called Recovery Groups), a mutual help organisation for people with serious mental illness in the USA. The aspects of empowerment were: provision of a peer-based support system, availability of an opportunity for role structure (i.e. allows individuals to take on meaningful roles within the group), and inculcation of a belief system that inspires members to strive for better mental health. Reissman and Carroll (1995) redefined mutual support group practice, suggesting that mutual support groups are helpful to facilitate the inner strengths of its membership and help them to remain self-reliant and empowered; the value of outside support resources such as the expertise advice from health care organisations can also be strengthened. Therefore, psychological empowerment is an appropriate construct to be applied in a support group, by which we can better focus on the beliefs of each family carer in the group such as whether they believe that their goals in relation to better coping with caregiving can be achieved. The awareness about resources and factors that hinder or enhance one's efforts to achieve these goals, and efforts to fulfil the goals should also be emphasised (Zimmerman et al., 1992).

Although a small-sized mutual support group may not be developed as those in organisational and community levels such as the Alcoholics Anonymous, Zimmerman (1995) suggested that the support group members can easily gain new opportunities to form inter-independent and outwardly radiating social relationships that will connect individuals to new people and ideas, and problem-solving skills in getting involved in group activities. Within a support group, empowering processes are those where group members create or are given opportunities to control their own destiny and influence the decisions that affect their lives. Mutual support groups, as an empowerment-oriented intervention, provide opportunities for participants to develop knowledge and skills from peers, and engage professionals as collaborators instead of authoritative

experts (Perkins & Zimmerman, 1995). This can be an empowering setting for family carers of patients with schizophrenia, providing opportunities for knowledge and skill development, development of a group identity, and establishing a more effective caregiving and harmonious family life.

3.4.2 Fostering help-seeking and affiliative behaviour

Social comparison theory provides another theoretical basis for studying mutual support groups. This theory postulates that social behaviour in a group can be predicted largely on the basis of the assumption that individuals seek to maintain a sense of normalcy and accuracy about their world (Festinger, 1954; Kessler, Mickelson & Zhao, 1997). In times of uncertainty and high level of anxiety, affiliative behaviours will increase as people seek others' opinions about how they should be thinking. Based on the findings of a study on illness experiences in four metropolitan areas and online forums in the US (Davison, Pennebaker & Dickerson, 2000), it was found that support seeking is highest for illnesses viewed as socially stigmatising and embarrassing such as AIDS, schizophrenia and other severe mental illnesses, or disfiguring such as eating disorder and breast cancer, leading people to seek the support of others in similar situations. In addition, this support seeking is also applied to the family members caring for these patients. On the other hand, this help-seeking behaviour is lowest for less embarrassing but equally devastating disorders such as heart and neurological diseases. Therefore, patients with diagnosis of schizophrenia, long-term psychiatric treatment and various kinds of life disruptions are more inclined to talk with others undergoing a similar challenge; and this motivated socialisation can also apply to their family members.

Family carers, similar to their relative with schizophrenia, have been forced to experience embarrassment and social stigmatisation by the very nature of the illness (Davison et al., 2000). The uncertainty of the illness and results of their caregiving, the burden of care, and the degree of readjustment required under the caregiving situations suggests motives only partially captured by terms like ambiguity and anxiety. In these situations, families' experiences set them apart from their immediate social environment and propel them towards others who have been similarly labelled as a family with a 'mad' or 'insane' member. While embarrassment might be thought to discourage affiliative behaviour, alienation from one's usual support network due to social stigmatisation may be precisely the kind of social anxiety that in turn increases

the values of the context of mutual support (Teichman, 1973; Davison et al., 2000). This suffering may elicit intense emotions and hence the desire to talk to others with similar problems and concerns in a trustful, secure and comforting social environment, for instance, the mutual support group that was facilitated by a registered psychiatric nurse and evaluated in this PhD study.

3.4.3 Reinforcing social learning between group members

As with some other group interventions or therapies, the mutual support group members can learn new adaptive behaviour from other peer members using three major elements of social learning: clear instructions, adequate reinforcement and effect of good models (Bandura, 1977). A support group usually consists of the major ingredients of mutual sharing and learning from each other's lived experiences during the group sessions. The group sets forth carefully considered suggestions, an action plan or mutually agreed instructions to help the individual eliminate or live more comfortably with their life problems. This will be similar to the major component of social learning – giving instructions for new behaviour (Glenn & Drew, 1992), which can motivate and give direction to participant's actions to achieve his/her goal(s). The effort of behaviour change is usually reinforcing as the group and the social environment positively appraise and approves the development of new skills and extinction of undesirable habits.

Support group sessions also encourage group participants to share positive and negative behaviours from the past or present. Members describe what their situation was like, how they have used their own and suggested ways of handling the problematic situations, and what their situation is like now (Helgeson & Gottlieb, 2000). Some support groups like most of the support groups for family carers, practice new behaviour in most of the group sessions. This sharing of lived experience and within-group practice in caregiving can encourage acceptance of their past, discourage denial of their present situation and encourage coping with the existing family problems. Group reinforcement nurtures a positive social environment for individual family carers to appreciate their accomplishment of overcoming unwanted behaviours or responses to the patient and mental illness, and on the other hand, to admit their faults and problems in caregiving. Desirable behaviours are therefore discussed and practised in the group sessions and/or in-between sessions; these behaviours can then be used in real family situations, where the problems are ordinarily manifested. If these

desirable behaviours and responses can be generalised to other life situations in which group members experience difficulty and distress, particularly those related to caregiving, they will find their interactions and sharing to be more reinforcing (Mankowski, Humphreys & Moos, 2001).

A mutual support group also encourages the less experienced family carers to emulate the veteran members, who are more experienced in caring for the patient with schizophrenia and thus can serve as models of learning. Kurtz and Powell (1987) suggested that the contributing factors of this vicarious learning were that: (a) the problems of the role models are similar to those of the relatively inexperienced group members; (b) the veteran members can describe the specific means used to bring about changes, thus, facilitating the success of problem-solving behaviour; (c) those veterans can demonstrate desirable behaviour and effective communication skills in real situations, which may be the same difficulties encountered by the other members; and (d) the veterans invite more interactions with other members because they admit freely that their well-being depends upon being able to share mutually their experience of caregiving with others. Because of their similar caring experiences, group members can list strengths as well as weaknesses of the new behaviours and make appropriate decisions about which actions to incorporate into their daily life, leading to ultimate goals for behavioural change (Kurtz, 1997). Nevertheless, behavioural change is not the only objective of a mutual support group and changes of cognitive perceptions and beliefs of life situations, particularly in patient care provision, are also important to reduce negative ideas and, thus, regulate the negative attitude and behaviour towards patient.

3.4.4 Inducing positive cognitive changes

Importantly, a person's cognitive processes can influence or shape their perceptions of the real world or their own personal situation (Yalom, 1995). These perceptions of relationship between self and the immediate environment can often complicate their emotional reactions and behavioural responses. Families with schizophrenia have been found to lack adequate knowledge about the illness and its care, leading to misunderstanding and misconceptions about caring for their mentally ill relative (Oldridge & Hughes, 1992; Kingdon & Turkington, 1994). The cognitive distortions in caregiving can lead to family distress, behavioural difficulties and finally burnout, if not addressed early on.

To correct these misconceptions and induce cognitive changes among the family carers in schizophrenia, mutual support groups have served the purpose of codifying the typical misconceptions held by the group members and developing a new belief system or ideology that corrects each member's understanding of the problems (Antze, 1979; Kurtz, 1997). In addition, group members misconceptions, distorted or irrational ideas, and over-generalizations (in particular, those are held in common by the group members) are discussed and challenged within the group. Thus the group members can choose from a variety of possible explanations provided by the other members to fit with their personal situation and to correct their specific misconceptions (Stewart, 1990; Mueser & Gingerich, 1994).

However, mutual support groups are highly cohesive as members have at least one key characteristic in common, such as being the family member acting as a primary carer. As noted by Powell (1994), the greater the similarity between an individual and a group, the more likely the group will exert durable important influence. One important aspect of the similarity between group participants is that group members can view themselves as 'average' (i.e. families feel that their difficulties and problems in caregiving are not so unique or unusual, but often are similar to those encountered by other families in the support group), but not as exceptional people with special problems. Individuals' belief of 'averageness' of their problems can help to reduce exaggerations of their individual problems and thus the feeling of stress (Krezman, 1985; Borkman, 1999). If the group members can accept they are just having an average problem that happens to everyone at times, they will more easily share their perceptions and feelings openly with each other.

Kurtz (1981) and Nowinski, Baker and Carroll (1995) have indicated that this belief of averaging and cohesiveness can reduce the exaggerated and dysfunctional feeling of shame and guilt among the members of the Twelve-step Groups (e.g. the Alcoholics Anonymous). Feelings of shame as well as stigmatised identities can be found in people who have chronic illness or disabilities such as patients with severe mental illness and their family carers (Loukissa, 1995). It can arise both from externally imposed prejudice and evaluations and also their unrealistic self-expectations in providing care to the ill relative while maintaining their own state of health (Cole & Reiss, 1993). Kurtz and Powell (1987) and Kurtz (1997) suggested that support group participants could experience some relief from feelings of shame and powerlessness following open sharing and identifying with or listening to others like themselves.

Their limitations and defectiveness in caregiving are no longer considered as shameful, but become qualification for group membership and reciprocal support. Chou et al. (2002) studied the effects of support groups on family carers of patients with schizophrenia in Taiwan, indicated that one of the reasons that the families reported satisfaction with support group experiences and showed improvement in burden and depression was their perception of getting assistance from and giving help to others with similar problems. As suggested by Yalom (1995), this feeling of 'universality' was considered as a very important element for the family carers in the study because they could talk freely and express their feelings to other participants not just of resignation but of helplessness, pain, fear, and more.

3.4.5 Summary

In viewing these theoretical perspectives, mutual support groups are complex entities that differ in important ways from professionally delivered help and highlight the importance and benefits of social support to the group participants. Support groups create positive lived experiences among group participants such as the inculcation of hope and belongingness, and the development of understanding about situations of self and social environment in relation to caregiving; all of these are thought to be therapeutic. They are also cognitive restructuring systems possessing elaborated ideologies about the cause and level of difficulty and about the way individuals need to think about their problems in order to be helped (Lieberman & Snowden, 1994). In addition, they form a new social network where people form interpersonal, trustful and helpful relationships, and in that sense, mutual support groups provide social affiliation and support (Powell, 1994). Nevertheless, as described below in the literature review (Section 3.5), there have been only very few empirical evaluations of this group intervention for family carers of people with chronic and severe mental illness in the past two decades (Biegel, Shafran & Johnsen, 2004) and only a handful of studies have examined the 'inside' group activities and process, which are essential in understanding the effectiveness of a therapeutic group intervention (Wituk et al., 2000). Penney (1997) also suggests that familiarity with mutual support groups is a crucial skill that professionals in a managed care system need to provide the most flexible and low-cost service for their clients. This PhD thesis empirically tested its efficacy for families of people with schizophrenia in Chinese culture, which is different in many ways from the Western cultures, in the settings of recent studies.

3.5 REVIEW OF THE EFFECTIVENESS OF MUTUAL SUPPORT GROUPS FOR FAMILIES OF PEOPLE WITH SEVERE MENTAL ILLNESS

There have been a number of literature reviews, which have examined the effects of family intervention in schizophrenia and other severe mental illnesses. However, these reviews have either focused primarily on a few approaches of intervention frequently used and empirically tested in mental health research such as psychoeducation programmes (Dixon, Adams & Luckstead, 2000), or examined only professional-led programmes and randomised controlled trials (Barbato & D'Avanzo, 2000; Pharoah et al., 2001). There is a notable omission of other alternative approaches of family intervention such as mutual support group, given the increasing emphasis of self-help programmes and family-based interventions in mental health services in the US, UK and other developed Western countries. The aim of this part of the literature review was to establish what is known about the effectiveness of mutual support groups for family carers of people suffering from severe mental illness, and so to identify the specific questions to be addressed in this PhD study. The main question of the review was "Are the mutual support groups effective in promoting health and other benefits for families of people with severe mental illness?"

3.5.1 Literature search strategy

This review of the research literature was based on the procedures suggested by the National Health Service Centre for Reviews and Dissemination (2001) Report Number 4 in the UK. Databases searched were Medline, Embase, CINAHL, OVID full text, PsycINFO, Cochrane Library, British Nursing Index, NHS National Research register, and System for Info on grey literature. The British Journal of Psychiatry, Schizophrenia Bulletin, Schizophrenia Research, American Journal of Psychiatry, and psychiatry and psychology journals published in Hong Kong or mainland China at the university libraries (i.e. both English and Chinese languages) were hand-searched and reference lists of all retrieved literature were also searched to identify studies that may have been missed. Leading researchers of current studies, as identified on the National Research Register, were contacted to ascertain whether a research report or paper relating to this intervention was due for publication during this review.

For electronic database searching, a combined free-text and thesaurus approach was adopted. 'Population' search terms included: serious mental disorder, severe

mental illness, psychos*, and schizophreni*. 'Intervention' search terms included: mutual support, mutual aid, social support, self help, group therap*, family therap*, family work, and family intervention. A sample search strategy is provided in Appendix 2. The search strategy was restricted to English-language research articles published from 1980 to 2005, except those imposed by the databases themselves. In fact, the review was conducted in various stages, i.e. before undertaking the study and then ongoing as the study was undertaken until December 2005.

Because of an expectation of a small number of research studies being identified, only two inclusion criteria were used to guide the search strategy: (1) the intervention used should be a client-led support group programme for families of a relative with severe mental illness; (2) both quantitative and qualitative research were selected. In addition, systematic review and meta-analysis of this topic were excluded. A total of 637 articles were retrieved from the electronic databases, of which one-fifth (n = 127) was found relevant and appropriate for further review. Hand searching, tracing unpublished or in press research reports, and screening reference lists increased the total number of articles retrieved for critical review to 146. After critical appraisal of these retrieved articles, 124 were excluded mainly because they were professional-led family groups (n= 98) and focused on education instead of mutual sharing and support among family carers (n= 26). Finally, a total of 23 studies are reviewed in this section, consisting of:

- Five using experimental or randomised controlled trial design on the effects of mutual support group on mainly family-related outcomes such as self-efficacy and coping with caregiving and family burden;
- Five using quasi-experimental design (non-equivalent comparison groups) on the effects of mutual support group on both patient and family-related outcomes such as patients' relapse and family burden;
- One using longitudinal non-equivalent group design (two time points at one-year interval) compared the levels of social support and community resources between support group participants and non-participants;
- Four using cross-sectional survey design compared the family carers' psychosocial conditions between support group participants and non-participants;
- Two using single cohort pre-test and post-test design examined the changes of family carers' psychosocial conditions over the period of intervention;

- Three using cross-sectional survey design examined the families' perceived benefits of support group participation to their psychosocial conditions;
- Three using qualitative design explored the family carers' perceived benefits and limitations of support group participation and their psychological changes during the group process.

3.5.2 Methodological quality of the studies reviewed

These 23 studies reviewed are summarised in Appendix 3. Most of these studies focus on families of patients with various types of chronic and severe mental illnesses in community mental health care. The majority of the family carers were female (mean 74.6%, median 76%, range 52% to 96%), middle aged (mean 49 to 61 years), parent or spouse (over 70%), elementary or high school education (about 63.1% in 11 studies), and white people (over 67%, a few studies did not report). Eight studies indicated that the families were from the middle social class (about 36.3% of total number of subjects in 23 studies); only one study reported that the families had low household income and two reported that 25% and 46% of the carers were employed.

More than half of the patients were male (average 67.8%, median 67%, range 40% to 73%) and on average more than 15 years of illness (15.8 years, range a few months to 35 years). The patients' psychiatric diagnoses were mainly: schizophrenia (range 42% to 100%), schizoaffective disorder and bipolar affective disorder (range 15% to 26%); however, three studies did not report the patients' psychiatric diagnosis. Their mean age was about 32 years (age range 16 to 88 years). Eight studies reported the patients' hospitalisations, ranging from 2.5 to 6 times, or zero to 31 days in the past six months. Only three studies reported the education level and working status of the patients (mainly primary school education and unemployed).

The studies mainly used one type of data collection method - a set of questionnaires or a qualitative interview; and only two studies (McCann, 1993; Winefield & Harvey, 1995) used two types of methods - a set of questionnaires and qualitative analysis of group process. More than two-thirds measured a variety of families' psychosocial conditions using standardised measures of family burden, social support, level of stress, coping ability, community service use, group benefits, and knowledge of mental illness; five measured family outcomes using self-designed or

non-standardised research instruments such as parents' preferences for help-seeking and group arrangement (Medvene et al., 1995), perceptions of information, coping, and support (Turnbull et al., 1994). In addition, only seven of them measured patients' outcomes such as relapse, psychiatric symptoms and functioning.

Major methodological limitations of the majority of the studies reviewed include non-probability samples, mainly non-experimental or cross-sectional descriptive study design, a great variety of standardised or self-designed family-related measures, and a very brief description of development, structure and content of intervention used. No included study made reference to a power calculation, and whether the included studies are sufficiently powered is open to question. About half of the studies reviewed were conducted in North America (12 studies) and only a few in the UK (4 studies), other European countries (2 studies) and Australia (2 studies). Otherwise, few studies reviewed were conducted in Asia (one in Israel, one in Taiwan and one in Hong Kong).

One or more participants withdrew from a study examining the effectiveness of how mutual support groups can affect outcomes, due to the disruption of the group dynamic. More than half of the studies reviewed did not report the attrition rate, while reported attrition rates varied (range 11% - 40%). Few reasons for attrition were reported and the reasons for discontinuation from the support groups (McCann, 1993; Winefield & Harvey, 1995; Heller et al., 1997), included inconvenience or not having enough time to attend, inadequate leadership, lack of comfort with other group members, and not having another person to take care of patient.

It is noteworthy that the structure and content of the mutual support group reported in the studies reviewed varied widely. For example, the period of intervention varied from very short, four 2-hour weekly sessions at a psychiatric unit to continuous, 1 to 2-hour weekly or monthly sessions affiliated to the Alliance of the Mentally Ill in the USA; and despite having a few common topics including knowledge of the illness and its treatment, principles of managing patient's problem behaviour and information about community resources, major components and format of the group sessions within the support group programmes were not clearly described or structured. This limits the potential for generalisation and replication of the intervention in future research and practice. It is also important to recognise that in more than half of the studies reviewed, the mutual support groups only included family members or main carers and patients were excluded from attending the group meetings. There was no

explanation of the rationale for the exclusion of patients' group participation. In addition, only five of the 23 studies reviewed have used a more rigorous research design (i.e. three experimental studies and two randomised controlled trial), few can provide empirical evidence on the effects of mutual support groups to family carers of patients with severe mental illness and clear implications for future research and practice.

3.5.3 Key findings of the studies reviewed on the effects and active ingredients of mutual support groups for family carers

Five experimental studies reviewed

Five of the studies reviewed used an experimental design (Albramowitz & Coursey, 1989 and Solomon et al., 1997, in the USA; Chien et al., 2005, in Hong Kong; Montero et al., 2001, in Spain; Szmukler et al., 2003, in the UK); they are summarised in Appendix 3. Three of them followed up the sample for six months (Chien et al., 2005; Solomon et al., 1997; Szmukler et al., 2003). The outcome measures used in these studies varied but most of them were family-related outcome measures, particularly family burden, self-efficacy, knowledge about the illness and its treatment, stress and coping ability, and social support measures. Only Montero et al. (2001) and Chien et al.'s (2005) study consisted of a few patient outcome measures, including mental state, symptom severity, functional level, and medication compliance assessment.

Albramowitz and Coursey (1989) reported that the family mutual support group showed significantly greater improvement in personal distress and management of family life, reduction of anxiety, and increase of community resources utilisation, when compared to routine community care. Solomon et al. (1997) compared the effects of a family support group with a brief individual family consultation programme and routine care, and reported that there was only significant improvement in self-efficacy regarding knowledge of mental illness and its treatment in the mutual support group and individual consultation programme immediately after intervention, when compared with the standard care. There were no significant differences in the other family-related outcomes between groups or over six months follow-up. For Montero et al. (2001) and Szmukler et al.'s (2003) studies, there were no significant differences in all measured patient and family-related outcomes between groups. Despite these studies reporting non-significant differences of treatment effects between

mutual support groups and other family treatment models over the follow-up period, all of them demonstrated that mutual support groups for families of patients with schizophrenia and other severe mental illness can induce positive changes for most of the outcome measures, immediately and up to six months after intervention. Chien et al.'s (2005) study in Hong Kong reported that Chinese family carers and patients in the mutual support group indicated statistically significant improvements on family and patients' psychosocial functioning at one week and six months following the intervention, when compared with their counterparts in the psychoeducation and standard care groups. However, these studies suggested that difficulties in engaging family carers in group participation and reducing their attritions in the group process imposed limitations to the findings of the mutual support group studies (Szmukler et al., 2003).

Quasi-experimental studies using a non-equivalent comparison group

The five quasi-experimental studies (Kane et al., 1990; McCreadie et al., 1991; Winefield & Harvey, 1995; Pickett & Heller, 1998; Chou et al., 2002) were conducted in different countries (i.e. the US, UK, Australia, and Taiwan) and compared the effects between mutual support group and routine psychiatric care or another type of multiple-family group intervention (i.e. psychoeducation and professional-led education) for family members caring for a relative with schizophrenia or another severe mental illness. The outcome variables varied widely and were mainly focused on family's psychosocial conditions such as social support, depression and burden.

McCreadie et al. (1991) was the only one of these five studies to measure patient outcomes. The study compared the effect of an education and support group (n=31) with routine psychiatric care (n=32) for family members of patients with schizophrenia, on patients' relapse rate in terms of re-hospitalisation and change in dosage of antipsychotic medication over 18 months follow-up. Results indicated that the re-hospitalisation rate and medication dosage in the mutual support group were only slightly reduced after intervention and over the follow-up period and there were no significant differences between the two groups.

Pickett and Heller (1998) compared the effects of a professional-led with a client-led family support group for 131 families of people with mental illness in Chicago and Southern Illinois. Despite finding no significant differences in coping ability and group benefit ratings between groups, the study indicated that the

intervention provided the participants with needed information about the mental illness and its treatment and improved their relationship with the patient. The researchers recommended that a joint collaboration between mental health professionals and peer family as co-leaders sharing their experiences and expertise in caregiving might work best for a family support group.

A few significant positive family-related outcomes of the mutual support group in three of the five studies reviewed included an increase in knowledge about the illness after intervention (Kane et al., 1990; Chou et al., 2002), family and peer support and positive attitudes towards the patient over 2-months follow-up (Winefield & Harvey, 1995), and a reduction of depression and burden over 1-month follow-up (Chou et al., 2002).

Two studies (Winefield & Harvey, 1995; Chou et al., 2002) collected qualitative data of families' feedback on mutual support group participation and its benefits using one open-ended question. Findings summarised from the written feedbacks indicated that most of the participants expressed satisfaction with the group experience and the perceived benefits for their group participation mainly included: increased confidence from sharing with others their concerns, emotions and difficulties in caregiving, learning some effective strategies and skills to cope with caring situations, and receiving useful information on mental illness and its management.

Non-experimental, comparative studies – single cohort, longitudinal non-equivalent groups, or cross-sectional, participants versus non-participants

Despite single cohort or non-equivalent groups being used in the seven studies reviewed (Cook, Heller & Pickett-Schenk, 1999; Gidron, Guterman & Hartman, 1990; Hellere, Roccofort & Cook, 1997a; Mannion & Meisel, 1996; Medvene et al., 1995; Sheridon & Moore, 1991; Turnbull et al., 1994), which might induce systematic sampling bias or limit the power of their replication and generalisation for future study of mutual support groups, their findings provided more information and insight into the potential therapeutic components of a mutual support group and the perceived benefits of group participation to family carers of people with schizophrenia and other severe mental illnesses. Heller et al.'s (1997a) study in the USA with a longitudinal, non-equivalent groups design compared the changes of social support and community service utilisation between mutual support group participants and non-participants over a period of one-year. The majority of the support group participants had the patient

living at home and and therefore greater demands of caregiving, but less service utilisation compared with non-participants. Heller et al. also found that the group participants highly valued some aspects of group participation such as: listening to others who share similar problems with adequate emotional support, providing systematic information about the illness and its treatment, and having the opportunity to share experiences and coping strategies of patient's symptom-related behaviour. Similar perceived benefits of support group participation were reported using a self-designed questionnaire and group interview, in one cohort of 29 parents of 17 young people with schizophrenia in Ireland (Sheridan & Moore, 1991) and another cohort of 55 family members at three adult psychiatric units in the US (Turnbull et al., 1994). Sheridon and Moore (1991) also indicated that for patients with more chronic illness, their families had more concerns about patients' illness prognosis, future life and family issues in relation to caregiving. Turnbull et al. (1994) identified from the qualitative data of group interview that the group participants benefited from an increased supportive network and greater involvement in the treatment process.

The results of the four cross-sectional comparative studies reviewed (support group participants versus non-participants) indicated that the mutual support group participants reported lower level of burden and more active and adaptive coping strategies for caregiving, than the non-participants. Three of them conducted in the USA showed that family carers' burden was associated negatively with their adaptive coping ability, education level, and group attendance, and patient functioning; on the other hand, it was associated positively with their service utilisation, depression and unmet needs, and patients' length of re-hospitalisations. Gidron, Guterman and Hartman's (1990) study of 50 parents of chronically mentally ill patients in Israel also indicated that support group participation encouraged employment of more active and interactive help-seeking coping strategies in caregiving, particularly among those with higher socio-economic statuses. However, contrasting with the other three cross-sectional studies, the support group participants in Gidron et al.'s study expressed higher level of stress due to greater concerns about difficulties in caregiving and relationships with spouse and patient and more guilty feelings concerning the patient's illness and care provision, when compared to non-participants. These participants in the support group also reported higher utilisation of family support resources available in the community than the non-participants.

Cross-sectional questionnaire surveys

A total of 757 families who participated in a mutual support group in different cities of the US were surveyed by mail in the three cross-sectional descriptive studies reviewed (Heller et al., 1997b; Citron, Solomon & Draine, 1999; Pickett-Schenk, Cook & Laris, 2000), using a set of family-related outcome measures. The common group benefits identified by the family members in all of these studies were: increased knowledge of the illness, its treatment and available services, and improvement of social support and coping with caregiving. Pickett-Schenk et al. (2000) suggested that such an increase of knowledge might also strengthen family members' coping with patient care. Results of Citron et al.'s (1999) study indicated that the families felt either personally more empowered or having a greater affiliation; and the longer the families participated in the support group, the more likely they were to experience benefits from the group participation. In addition, the family members who showed greater burden and stress were those who were parents (vs. other relatives), with greater involvement in caregiving and perceiving more disturbing behaviour from the patient. Heller et al. (1997b) emphasised the positive associations between perceived social support, knowledge of illness and its treatment and relationship with patient and other family members. Therefore, mutual support group participation encourages more social support within and outside the group, including exchange of knowledge about the illness (informational support), assistance and practice of effective strategies in caregiving (instrumental support) and sharing of experiences and feelings concerning patient care (emotional support) among family carers in the group, which may improve their relationships with the patient and other family members.

Qualitative exploratory studies

As yet, little is known about the various factors that are beneficial to the participants of mutual support groups for family carers of patients with severe mental illness. The three qualitative exploratory studies reviewed attempted to increase the understanding of the factors perceived as helpful by family carers in support group participation. Two of them were conducted in European countries and one in Australia; different methods of data collection were used. McCann (1993) evaluated the group progress and benefits to 21 relatives of inpatients with mental illness in a psychiatric hospital in the UK, using the minutes of 12 monthly sessions of a support group. Winefield, Barlow and Harvey (1998) tape-recorded 36 participants' responses during

meetings of support groups for family carers of people with schizophrenia in Australia, whereas Lemmens et al. (2003) in Belgium collected data on perceived therapeutic factors and positive experiences in a support group from 12 family carers of patients with different types of severe mental illnesses, group facilitators and group observers using a self-report, open-ended questionnaire.

From these data of formative evaluation on family support group, a few common perceived benefits of group participation were identified, including: information of the illness, its treatment, available services, and effects of medication, respect and support from group members and professionals, and better coping with caregiving situations. Moreover, McCann (1993) indicated that family carers emphasised their confidence in conducting the group themselves; and from group participation, they gained more hope of patient recovery and involvement in patient care. Winefield et al. (1998) indicated that long-term frequent and consistent mutual support group participation would increase family carers' sense of control in caregiving and reduce their burden of care. However, length of caregiving experience may affect their involvement and responsiveness to group discussion and activities; thus the results of the study showed that the family carers with more caregiving experience were more involved in the support group and perceived group participation to be more beneficial to them. Lemmens et al. (2003) found that the perceptions of important aspects of a support group might differ between family carers as participants and health professionals as facilitators or observers. The family carers indicated that the process aspects of the support group such as experiencing communality of the caregiving situation with other group members and gaining insight from others' sharing of experiences and coping methods of difficult situations concerning patient care are very important and helpful to them, whereas the professionals emphasised the group structure and climate such as enhancing group attendance, involvement and adequate support from group and provision of specific interventions to meet individual needs as being more important.

3.5.4 Summary of what is known about the effects and active elements of mutual support groups for families of people with schizophrenia and unanswered questions

Mutual support groups are informal networks of individuals who share a common experience or issue. What emerges from the studies reviewed in Section 3.5

is that they can be effective in building participants' personal skills, empowerment and social support. Different self-help programmes and initiatives are widely used across Canada, the US and the UK for a wide range of sectors of the populations such as those with grief and bereavement, chronic physical diseases and substance abuse (Carpenter, 1997; Lorig et al., 2000; Mankowski et al., 2001), and have attracted a great deal of research attention. However, from the results of the literature review reported in Section 3.5, few research studies hitherto have investigated the helping process and effects of mutual support groups for family members in caring for a relative with severe mental illness. Family mutual support studies for schizophrenia and other severe mental illnesses in Western countries is replete with cross-sectional surveys, prospective cohort studies and quasi-experimental approaches with non-equivalent groups, emphasising the apparent benefits of group participation in maintaining the psychological and social well-being of family carers (Heller et al., 1997a). While there exists a solid foundation of support group research in both quantitative and qualitative approaches describing some types of problems within these families typically addressed such as improved access to information and community resources and perceptions of greater social support (Kane et al., 1990; Winefield et al., 1998), there is relatively little empirical evidence which supports enthusiastic claims of their benefits in improving family functioning and patients' mental conditions, and in satisfying families' immediate and long-term psychosocial needs (Szmukler et al., 2003). Thus it may explain why recent reviews of clinical trials of family intervention for schizophrenia (Mari & Streiner, 1996; Barbato & D'Avanzo, 2000; Pharoah et al., 2001) do not include any study using a mutual support group approach.

Only one of the five experimental studies reviewed (Chien et al., 2005) showed that mutual support groups were more effective in producing a variety of long-term health or other benefits for family members when compared with other treatment models, such as cognitive behavioural approaches. Nevertheless, these studies demonstrate that mutual support groups can produce consistent short-term positive impact for family carers, such as knowledge about the illness and its treatment, self-efficacy in caregiving and family functioning. Significant longer-term benefits (i.e. at least one year following intervention) have not been demonstrated possibly because of methodological limitations on study design and organisation, facilitation and progress monitoring of the intervention. For example, Szmukler et al. (2003) highlighted the

difficulties of getting families to engage in the support group which resulted in a low rate of group attendance (38% attended less than half of the group meetings). In addition, the length of the support groups varied widely, ranging from one and a half months to more than one year; and the content and format of the intervention, peer leadership, group facilitation by professionals, and interactions and mutual helping between participants within and outside group meetings were not clearly defined. As suggested by Biegel, Robinson and Kennedy's (2000) review of experimental studies of family intervention for people with schizophrenia, lengthy interventions with comprehensive content and appropriate format are associated with greater improvement in patients' recovery and more positive family outcomes. Therefore, the variations and ambiguities identified in the design of the support group programmes in these five studies, and also in the other non-experimental studies reviewed, might also have affected findings on the effectiveness of a mutual support group in promoting family health.

The three qualitative studies reviewed attempted to explore the perceived benefits of family members participating in a mutual support group and their feedback on the strengths and limitations of the group. In one of the qualitative studies reviewed, Lemmens et al. (2003) acknowledged that there has been little research on the process of change in multiple family group intervention for schizophrenia and other mental illnesses. The described curative factors and mechanisms of change in the literature consist mainly of impressionistic accounts by therapists of what they believed to be the most important factors according to their clinical experience, such as generating new perspectives on illness and family roles (Stein & Wemmerus, 2001), experiencing hope and positive growth (Asen, 2002) and identification with the experience of their counterparts in other families (Bishop et al., 2002). In fact the notion of the mutual support group and other approaches of family intervention is multi-faceted and complex (Pharoah et al., 2001). It is also noteworthy that little is known about the therapeutic components of mutual support groups, as well as psycho-education and other approaches to family intervention for schizophrenia, which are perceived as beneficial to the participants themselves. Lehman and Steinwachs (1998) and Brooker (2001) suggested that the reluctance of clinicians to use family intervention might be attributed to inadequate knowledge of researchers of the key elements within family intervention, which enhance its therapeutic effects for family carers and patients. Increased understanding of the perceived therapeutic aspects and

active ingredients of family intervention, such as the mutual support group in this PhD study, would facilitate the design of interventions for family carers of mentally ill patients and thus produce optimal benefits for patients and their families.

Only two of the 23 studies reviewed were conducted using a sample of Chinese people in Hong Kong and Taiwan (Chien et al., 2005; Chou et al., 2002). In Chinese populations, limited studies are reported using the mutual support group as the approach of family intervention in schizophrenia; and psychoeducation programmes is the most commonly reported model of family intervention for these patients (Xiong et al., 1994; Chou et al., 2002). In Hong Kong, mutual support groups have been more commonly used than in mainland China. They have been organised as very brief programmes with only three to four sessions held at a health care centre by social work students or community psychiatric nurses (Ma & Yip, 1997); however, they are often lacking a well-structured protocol and/or systematic monitoring of the group development and progress (Pearson & Ning, 1997). Therefore, there is a need for formal evaluation of short and long-term effects of mutual support groups, which originated from the West, on families and patients' health conditions in Hong Kong and other Chinese populations. This PhD attempted to fulfil this need to have an evaluation of a mutual support group programme for family carers of Chinese people with schizophrenia in Hong Kong over a 12-month follow-up period.

Most of the studies reviewed focused mainly on chronic mentally ill patients in community care settings (an average of more than 15 years of illness, ranging from a few months to 35 years) and the support groups were mostly facilitated by social workers, psychiatrists or psychologists rather than psychiatric nurses. Due to the methodological limitations of the studies reviewed including non-probability sample, non-equivalent groups or cross-sectional design, and a wide variety of research instruments used, the effects of the support group programmes remains unclear and inconsistent. In addition, the outcomes of the studies reviewed mainly focused on families' health conditions and only a few also included the patients' health-related outcomes. More than two-thirds did not follow up the study participants and test the long-term effects on them after intervention. As a result, many questions about the effects of mutual support groups for family carers of people with schizophrenia and other severe mental illness on either the families' health condition or patients' recovery remain unanswered. Nevertheless, the methodological shortcomings such as

the lack of sensitive outcome measures and convenience samples may have contributed to the lack of consensus between studies.

The majority of the studies reviewed had only a very brief description of the group intervention used, no specific protocol or clear guidelines for the group sessions, and unknown procedures or mechanisms for monitoring the group progress. Failure to provide a clear description of the content and process of mutual support groups in the study report reduces our understanding of the intervention used and may limit replication of the intervention and its evaluation in other samples. In addition, limited focus made on the establishment of trust, belongingness and harmony in the early stage of group development and the provision of continuous encouragement and support to each family carer throughout the group participation may have reduced the motivation and interest of the carers in attending the group, thus increased the dropout.

3.6 RATIONALE FOR THE EVALUATION DESIGN USED IN THIS PHD STUDY

This PhD study aimed to evaluate the effectiveness of a mutual support group intervention for family carers of people with schizophrenia. Issues surrounding evaluation of a community-based psychosocial intervention as used in this study are of equal importance to clinicians and researchers delivering care in mental health care services, and the dearth of evidence for best practice can create uncertainty about how health gains can be optimised for the service users (Griffiths, 1999). Thus, it is important to look at the theoretical issues of evaluation of health care services or intervention, rationale for using a randomised controlled trial design for outcome evaluation, as well as the need for a process evaluation using qualitative approaches.

3.6.1 An overview of approaches to health care programme evaluation

Evaluation of health care programmes or interventions can be conducted by means of an assessment that aims only to provide useful information about an intervention within a specific social context. It can be done using a cross-sectional survey and a longitudinal prospective or retrospective study approach to detect associations between an intervention and an outcome but cannot rule out the possibility that the association has been caused by other uncontrolled variables. Non-random allocation or perceived views of subjects by researchers may also induce systematic differences between the treatment group and the non-equivalent comparison

group, thus affecting the treatment outcomes and the reliability and validity of the findings (Pawson & Tilley, 1997).

Health services evaluation and research can also apply to a careful and comprehensive investigation of both the process and outcomes of the intervention, which can generate new knowledge applicable to practice and research in other health care settings. A combined use of summative and process evaluation for the mutual support group in this study can be appropriate to serve the purpose of evaluation, that is, to understand and determine the value of the intervention. Process elements of the support group in this study, which describe how an intervention works, and its outcomes, which indicate the effects of the intervention on the participants' health status and determine the level of success achieved, are believed to be pertinent and important to explain the usefulness of the intervention to the families in need. Although other methods of evaluation such as pluralistic (multiple sources of information), illuminative (ethnographic and interpretive) and evolutionary (action research) approaches have proved useful in unravelling the complexities of implementing and affecting changes in community-based health promotion programmes, data collection can become unfocused which impacts upon ease of analysis and interpretation (Billings, 2000). In addition, Milburn et al. (1995) argue that the use of complex, mixed methods of evaluation may produce contradictory results.

Process evaluation focuses on observation and documentation of the programme activities, personal events, ideas and opinions, social interactions between participants, and other aspects of the history of the programme, highlighting in particular key decision points and features of implementation (Dehar, Casswell & Duignan, 1993). Tones and Tilford (2001) contend that process evaluation can accumulate evidence, which illuminates the reasons for success or failure and provides guidance for improvement of the intervention. They also suggest that this approach is best suited to qualitative methods of data collection that includes observation, interviews, tape records and documentary analyses and generates framework or model of practice that have potential for replication.

Summative evaluation of health care intervention concentrates on changes in outcome measures such as physical and psychosocial well-being of the participants and services utilisation, matching the outcomes against the stated objectives (Dehar et al., 1993). Generating this empirical evidence of the effectiveness of the intervention

under study, it is commonly accepted that an experimental design should be first considered to determine whether or not the objectives set have been achieved, or to compare the relative effectiveness of alternative approaches to fulfilling the objective stated. However, it is important but difficult to choose sufficiently comprehensive and sensitive standardised outcome measures that detect changes in individual behaviour, attitude and health status in the pre- and post-intervention measurements. In addition, it is argued that summative evaluation tends to neglect the process of any intervention, which may leave researchers and clinicians with insufficient knowledge of why an intervention has succeeded or failed (Pawson & Tilley, 1997). Whilst the use of selective outcome measures is criticised for their snapshot focus, their use alongside the process methods may result in complementary contributions to the success of evaluation of an intervention, for instance, evaluation of the effects of the family mutual support group used in this PhD study.

3.6.2 Rationale for using a randomised controlled trial design

For outcome evaluation, an randomised controlled trial (RCT) is a well-established approach to scientific investigation that makes use of a series of measurements or observations on selected variables under conditions well controlled by the researcher (Sibbald & Roland, 1998). Other study designs such as prospective or retrospective approach using cohort group or two non-randomised groups can detect associations between an intervention and an outcome; however they cannot rule out any systematic differences between the study groups or systematic bias caused by preconceived views of subjects, clinicians and researchers toward the assessment of outcomes. According to the Medical Research Council (1998), an RCT is the most powerful method available for testing the cause and effect relationships between dependent and independent variables and is most appropriate for assessment of the effectiveness of a new intervention or service compared with the routine or standard care. Hence the RCT was selected as the research design for this PhD study to test the hypotheses of whether mutual support group intervention is more effective in improving psychosocial health statuses of family carers and their patients with schizophrenia compared to routine psychiatric care.

However, Altman et al. (2001) emphasise that clinical trials with inadequate methodologic approaches are associated with exaggerated or biased treatment effects; and many reviews have documented deficiencies in reports of clinical trials and thus

reported results may be misleading. More than half of the RCTs published in medical and other health care journals did not report clearly one or more aspects of the study, such as the design, data collection procedure, data analysis strategies, and results, and this will provide inadequate information to place any confidence in the validity of the trial (Schulz et al., 1995).

Matthews (2000) also argues that it may sometimes be difficult to maintain a well-controlled experimental environment in frequently changing clinical practice settings, and to apply important techniques of a RCT, such as blinding of subjects or clinicians to interventions and subjects' refusal to receive specific treatment. Bias even appears in trials if researchers fail to prevent foreknowledge of treatment allocation by inadequate allocation concealment, thereby causing greater variability in estimates of treatment effects (Gillman & Runyan, 1984; The Standards of Reporting Trials Group, 1994).

In response to these criticisms, the Consolidated Standards of Reporting Trials (CONSORT) statement (first published in The Journal of the American Medical Association in 1996) has been supported to be a widely adopted guideline to facilitate proper design and execution of clinical trials (Begg et al., 1996). The revised version in 1999 consists of a checklist of 22 items for reporting a RCT and a flow diagram showing the flow of participants through each stage of a trial (Altman et al., 2001), and will be used as the methodological and documentation standard for this PhD thesis. This statement can provide key and helpful information necessary to evaluate the internal and external validity of the report. Using this standard, the readers can judge whether the treatment effects and findings are likely to be reliable.

3.6.3 A need for process evaluation

The changing nature of service delivery makes questions about the process and user satisfaction as important as those about treatment effectiveness. Evaluation should be built into new and existing services or interventions, looking at both outcomes and formative aspects of the intervention and the process of achieving the intervention in practice. One of the most important aspects of designing an evaluation strategy is to include not only the outcome measures for the users but also the process data of the intervention, and the users' actual experiences and difficulties encountered during the intervention, thus presenting a balance between summative and formative evaluation (Rossi & Freeman, 1993). It may be a more simple procedure to present a single

summative conclusion, while at the same time overlooking the need for information concerning how an intervention actually worked or could be modified; for example, in this study, what steps were necessary to strengthen group development or which components were perceived by the participants as most beneficial or helpful in their group participation.

The inclusion of qualitative measures in all kinds of medical and health research has been promoted as a way to close the gap between the sciences of discovery and implementation (Fitzpatrick & Boulton, 1994; Barnes, Stein & Rosenberg, 1999). Weiss and Greene (1992) suggested that qualitative methods are particularly appropriate for family support and empowerment programmes, in which family members and their patients should be treated as partners in the evaluation process. Being the users of the mutual support group evaluated in this PhD study, perceptions of these family carers of the usefulness of the support group in terms of individual, patient, family, and group levels are of ultimate importance as well as our interest in understanding the effectiveness of the intervention. It is essential to know about the context in which the group developed and the ways in which the carer's life might be influenced both by their difficulties encountered and resolved and the group intervention used. By establishing the reasons behind certain behaviours of subjects under study, a qualitative approach can help to identify barriers to practice change (Grol, 1997).

Open-ended qualitative interviews and tape recordings of all group sessions used in this study are likely to be effective ways of revealing this kind of information. The use of these qualitative methods involves the systematic collection, organisation and analysis of textual material derived from verbal interactions and observations. It is rooted in the interpretive perspectives found in humanity and social sciences that emphasise the importance of understanding, from the viewpoint of the people involved, how individuals and groups interpret, experience, and make sense of social phenomena (Pope, van Royen & Baker, 2002), such as the social interactions and learning process during mutual support group participation studied in this PhD. Maton (1993) suggests the importance of shifting the focus of research on support groups from understanding only the outcomes of the group intervention to the interactive process of the group, in which adaptation of group members is a result of interchange between participants within an interactive environment involving modification of their behaviour that enhances their abilities for further interchange; and involves

assimilation and accommodation of important information received from participants' sharing and interactions. The emphasis in these qualitative methods on understanding meanings and experiences make them particularly useful for quality assessment (particularly in identifying the strengths and weaknesses of the intervention from perspectives of service consumers) and unpacking some of the complex issues inherent in quality improvement of the intervention used.

In addition, formative evaluation including basic information about the characteristics of family carers recruited to the intervention, those who dropped out from group intervention, and their levels of compliance (i.e. group attendance rate and reasons for dropout) are essential. The outcome and process data analysed with consideration to these data can be elucidated to find out why, for instance, one subgroup of families respond better to a mutual support group than another, or why certain part of the programme leads to poorer client satisfaction. This strategy for evaluation is being commonly used in public health services such as health education and illness prevention programmes and can purposively be applied to the community-based family support group programme in this PhD thesis.

3.7 CONCLUSION AND CONTRIBUTION OF THE PRESENT STUDY TO KNOWLEDGE

An increasing recognition and acceptance of mutual support groups as a means of helping patients with chronic and severe mental illness and their families is part of a broader self-help movement that has progressed worldwide, particularly in the USA, attracting people who encounter common problems to group together for mutual help and emotional support. As discussed in Sections 3.2 and 3.3, studies have shown that social support and positive social interactions provided by a network or system of 'significant others' can help an individual mobilise his/her resources so as to mediate or buffer stress encountering and to cope with burden in caregiving, thus improving one's mental health. Whilst differed quality and quantity of social support can be provided, family mutual support groups have been designed in response to the needs of these family carers in availing themselves of social support from others in similar situations and physical and psychosocial needs concerning caregiving.

Theoretical models discussed in Section 3.4 such as stress-vulnerability and coping, and social comparison and social learning theories highlighted the important concepts applied to and the potential effects of the support group on providing an

appropriate social environment in which they can affiliate with other family carers to explore a new adaptive role in caregiving, and explained why it helps to develop a new belief system or ideology that corrects each member's understanding of the illness and problems in caregiving. In viewing these theoretical perspectives, mutual support groups are complex entities that differ in important ways from professionally delivered help and highlight the importance and benefits of social support to family carers as group participants.

From the review of studies from 1980 to January 2006 described in Section 3.5 on mutual support groups for family members of people with severe mental illness, there is little empirical evidence supporting the significant effects of mutual support groups on families' psychosocial well-being and their patients' health conditions. A number of non-experimental studies on mutual support groups conducted in different Western countries demonstrated a variety of benefits of group participation reported by the group participants such as increasing knowledge about the illness and its treatment, reducing burden and distress, and enhancing coping ability and social support. However these studies lacked rigorous control and most did not use standardised and valid instruments as outcome measures and did not schedule follow-up to examine the long-term effects of support groups to family members. In addition, only two studies were conducted in Chinese populations, although the findings in these studies indicated positive effects of mutual support group to family members of people with schizophrenia.

The literature reviewed in this chapter highlighted the importance of an RCT design to evaluate the effectiveness of a mutual support group for Chinese family carers of people with schizophrenia, and to investigate its effects over time (one week and 12 months after intervention) on families and their patients' health statuses. The review also highlights the need for this study to examine the benefits and therapeutic mechanisms of the support group as perceived by the group participants and to describe its stages of development and limitations from analysis of tape-recorded data of group sessions. The current study built on the findings of the previous studies of family mutual support groups but addressed some of the important issues indicated in the literature review in this chapter and Chapter 2, which most other studies neglected, as follows:

- This research paid more attention than most previous studies to treatment integrity, which is recognised to enhance the effect of an intervention and increase the power of the study and validity of the results. A randomised controlled trial design was used, with a treatment protocol to guide the intervention, to evaluate the effectiveness of the mutual support group compared to the routine psychiatric outpatient care. This research design enhanced the statistical power of the study and thus increased the significance and generalisability of the findings;
- The study demonstrated a comprehensive follow-up of data from families and patients in order to understand the reasonably substantive effect of family intervention. In addition to a 12-month follow-up of families and their patients after the intervention, the study examined a variety of psychosocial outcomes of families including: caregiver burden, family functioning, social support, and services utilisation by family carers and the daily functioning, mental status and re-hospitalisation of their relative with schizophrenia, using standardised and valid instruments or measures;
- The study tested whether a psychiatric nurse who received only 3 days training from the author to ensure his competence to facilitate the support group, could produce outcomes, which are similar to those of previous studies in which group facilitators received substantially more training, as cognitive behaviour therapists, for example Haddock et al. (1999);
- The study gave very careful consideration to the socio-cultural conditions, which might influence the structure and process of the support group and could be one of the important factors of a successful family intervention and adapted the intervention to meet these conditions. For example, in treating Chinese families, it is important to recognise the family functions and processes, and to respect and utilise these in the intervention (Bae & Kung, 2000). The mutual support group emphasised Chinese ways of communication (i.e. characterised by mutual respect and an emphasis on positive practical help and actions for family members rather than talking) and sought to establish mutual trust and respect between group participants in the first two group sessions. More emphasis was placed on maintaining family traditions, rituals, relationship, and communication, particularly between family carer and patient;

- Finally, the study conducted a concurrent and retrospective process evaluation of the support group using qualitative methods to identify the perceived benefits and therapeutic mechanisms of the group intervention from the perspective of families after intervention, together with an analysis of taped sessions to identify the development of the support group and changes in the experience of individual members and the group overall over the course of treatment.

In summary, this PhD study evaluated the effectiveness of a mutual support group model of intervention to Chinese family carers of patients with schizophrenia in community mental health care in Hong Kong, using a well-structured and culture sensitive, pragmatic trial. The findings of this study may add to existing knowledge of family intervention for patients with schizophrenia and may be drawn upon by mental health professionals in the selection and design of appropriate intervention for families providing care to a relative with schizophrenia.

CHAPTER 4 DEVELOPMENT OF MUTUAL SUPPORT GROUP PROGRAMME AND ITS PILOT TESTING

4.1 INTRODUCTION

This chapter presents the background, structure and content of the mutual support group programme used and evaluated in this PhD study. This intervention protocol (described in Sections 4.2 to 4.8) was used by the group facilitator in the study to guide the group development and meetings in the prescribed manner, establish consistency of implementation of the group intervention, and enhance its replicability in future study. Phase 2 of a two-phase pilot study of the group intervention was conducted from June to December 2002 to test the support group intervention protocol and procedure, its feasibility, and the impact on 24 family carers immediately after the group intervention (when compared with a control group of 24 family carers) is also presented. Section 4.9 presents a summary of the results of the pilot study. This is followed, in Section 4.10, by changes to the group intervention, on the basis of the pilot study, which were implemented in the main study, the findings of which are reported in Chapters 7 and 8.

4.2 DESIGN OF THE MUTUAL SUPPORT GROUP INTERVENTION

As discussed in Chapters 2 and 3, the demands for community care for people with schizophrenia and other severe mental illness has increased both in Western countries as well as in Hong Kong. There is a growing realisation that many families need psychosocial support when caring for a relative with schizophrenia; and for one reason or another, these families cannot benefit from individual therapy. This is especially true of those families whose lifestyle is characterised by inadequate support from their natural social network, such as relatives and friends. Indeed, these families need social support as well as educational and psychological interventions. Advocates of group interventions, such as mutual support groups for families of people suffering from schizophrenia, point to the advantages of groups over individual interventions. For example, they enable family members to benefit from the experience of others in a similar situation to themselves (Reissman & Carroll, 1995). In addition, the theoretical perspectives explaining the potential benefits of social support to illness prevention and health promotion for family members caring for a relative with mental illness were presented in Chapter 3.

In this PhD study, a mutual support group intervention designed for Chinese family carers of patients with schizophrenia in Hong Kong was based on the widely accepted belief that mutual support has the potential to provide preventive interventions involving the mobilisation and optimisation of social support among families in common stressful predicaments, anticipating stressful life events, or transitions throughout the caring process of their relative with schizophrenia (Gottlieb, 1988; Helgeson & Gottlieb, 2000). Definition of mutual support groups used in this study can be referred to a widely quoted and used definition by Katz and Bender (1990). They suggested that mutual support groups are voluntary, small group structures which are "usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desirable social and/or personal change" (p. 23). The organisers and members of such groups may perceive that the group participants' needs are not, or cannot be, met by or through existing social institutions. These support groups emphasise face-to-face social interactions and the assumption of personal responsibility by members. The groups often provide material assistance as well as emotional support and promulgate an ideology or values through which members may attain an enhanced sense of personal identity.

Wasserman and Danforth (1988) suggest that supportive group intervention can be organised around facilitating the mastery or reducing the incidence of particular stressful life events. Development of an additional social support system increases both individual and collective competencies for resolution of these stresses. Therefore, support group work is considered a natural way of bringing people together, who can help each other overcome their common suffering and prevent any severe psychological disturbances, and even the development of mental disorders.

This treatment protocol was designed by the researcher on the basis of recent literature in relation to the successful practical experience and difficulties encountered in establishing a mutual support group for patients with schizophrenia and their family members, and also a recent health needs assessment of families caring for a relative with schizophrenia in Hong Kong conducted as part of the preparation work for the present study (Chien & Norman, 2003). The findings of the needs assessment highlighted a few educational needs perceived as important by family carers of patients with schizophrenia, including gaining information about early warning signs of illness and relapse, effects of medication and ways of coping with patients' bizarre and

assaulting behaviour. These important needs were included in the mutual support group programme tested in this study. The researcher also took into account his experience of the psychiatric rehabilitation and group development in mental health settings in Hong Kong, in developing the protocol for this mutual support group intervention. The structure and principles, roles of facilitator and peer co-facilitator, and potential obstacles of the mutual support group programme used in this study are described below.

4.3 STRUCTURE OF THE MUTUAL SUPPORT GROUP

In mutual help or support, people with similar caring or life problems are potential help-givers, more inter-dependent than dependent. The essence of the mutual support group is giving help and at the same time benefiting from giving (Reissman, 1997). This mutual support group designed for family carers of patients with schizophrenia was aimed at serving the purpose of reciprocal support and assistance amongst the family carers. Thus it represented what the group and the community could do for the family carers and their patients, which might not be developed by health professionals.

During the six-month mutual support group intervention, family carers had to attend 12 bi-weekly sessions (i.e. group intervention over a period of at least six months is suggested to have substantial effects on participants in family psychosocial interventions, as reported in systematic reviews by Barbato and D'Avanzo (2000) and Pharoah et al. (2001)). Each session lasted approximately two hours. Key elements of the support group programme used in this study are summarised in Table 4.1.

The timing of meetings for this support group was decided through common agreement of the group members during the group sessions. Content of the group sessions varied, and the group decided this. It consisted mainly of group discussion, information giving about schizophrenia and treatment by one group member, watching a video and giving feedback, sharing experiences of caregiving and methods of patient management, role play, and behavioural rehearsal of learned skills from group members or the facilitator. All group sessions involved supportive interventions such as ventilation of feelings, sharing stressful experiences, validation of caregiving experiences, encouragement and praise for providing care, affirmation of the family's coping ability, and support for struggles with difficult situations and disturbing behaviours of patients. The support group also focused on enhancing participants' self-

Table 4.1 Key Elements of Mutual Support Group Programme

1. Overall structure:
- Twelve bi-weekly sessions (around six months) and each session lasted about 2 hours;
- It is facilitated by one registered psychiatric nurse who was trained in group facilitation and co-led by one or two peer participants;
- Timing of meeting was decided through agreement of group members;
- Format of group sessions varied according to the content of each session, such as group discussion, video show and giving feedback, role play, and behavioural rehearsals;
- All group sessions involved supportive interventions such as ventilation of feelings, validation of caregiving experiences and affirmation of coping ability;
- It consisted of five-phase group development and is described in Section 4.7.

2. Five group phases and themes (refer to Section 4.7 for details):
- Phase 1 - Engagement (Session 1 – 2)

- Theme: Who we are; we need to share our experiences and feelings
- Phase 2 - Recognition of psychological needs (Session 3 – 5)

- Theme: Being aware of and accepting our feelings and reactions
- Phase 3 - Dealing with psychosocial needs of self and family (Session 6 – 8)

- Theme: Understanding about our relative's needs and available community resources
- Phase 4 - Adopting new roles and challenges (Session 9 – 11)

- Theme: Recognising and adapting to new roles and challenges in caregviing
- Phase 5 – Ending (Session 12)

- Theme: Conclusions - Where will I go from here?

3. Nine principles to strengthen mutual support:
- All-in-the-same boat
- Mutual aid and support
- Reciprocal demands of giving help and being helped
- Self-determination
- Sharing information and personal assets
- Dialectical process
- Discussing a taboo area
- Individual problem solving
- Behaviour rehearsal

4. Role of group facilitator:
- Encouraging and modelling information giving and sharing;
- Eliciting and mediating differing opinions;
- Giving advice to discuss taboo areas;
- Insisting of the need for lifestyle and family role changes;
- Calling attention to members' shared situation;
- Reinforcing and demonstrating empathic responses;
- Supporting mutual demands;
- Allowing individual problem solving;
- Engaging members in behavioural rehearsals with risk assessment.

5. Role of peer co-facilitator:
- Assisting and encouraging personal disclosure;
- Accentuating social approved behaviour;
- Encouraging increased sense of control and mutual helping;
- Providing guidance and information about group meeting and resources;
- Reinforcing inter-dependence and group cohesion;
- Acting as a role model to establish trust and confidence amongst participants.

efficacy in coping by: (a) reviewing similar situations and experiences from every group member, whether they have dealt with them successfully or not; (b) making the caregiving situations more manageable using problem solving strategies and social learning from models or veterans within the group; and (c) altering the cognitive and emotional reactions to these situations by clearing up any misconceptions and unrealistic self-expectations, and getting the group members to see themselves as 'average' or 'similar' when dealing with the difficulties faced commonly by all the families caring for the patients. The content of each mutual support group is outlined in Table 4.2 in Section 4.6. Family carers of the support groups were permitted, and were sometimes encouraged, to meet with each other outside the formal group meetings.

The five-phase development of the support group is described in Sections 4.6 and Appendix 4. The concept of phases or stages of group development is generally accepted by health professionals when using this modality of support group intervention (e.g. Powell, 1994; Galinsky & Schopler, 1995; Wilson, 1995). The use of phases, instead of definite tasks or topics of each group session, allows flexibility in time and task achievement, and is thought to foster the development of trust, autonomy, closeness, and interdependence, and even successful termination of group (Wilson, 1995). Content and themes of the group sessions were reviewed and modifications were made based on the findings of the pilot study. The major modifications included: careful consideration of the participants' involvement and personal development in the group; the inhibitory factors influencing group and individual benefits; facilitation on establishment of group ideology and consensus; and induction of professional and additional support outside the group. Nine principles to strengthen mutual support were emphasised within the group and served as the basis of interactions between the group members during meetings. These principles included: 'all-in-the-same boat', 'mutual aid and support', 'reciprocal demands of giving help and being helped', 'self-determination', 'sharing information and personal assets', 'dialectical process', 'discussing a taboo area', 'individual problem solving', and 'behavioural rehearsal', and are described in Appendix 4.

The support group sessions were conducted at a seminar or in an interview room of the outpatient clinics under study by one group facilitator, who was a registered psychiatric nurse, had previous experience of conducting group intervention, and had received training in group facilitation organised by the researcher. The content of the three-day training workshop of the group facilitator is presented in Appendix 5.

As suggested in the literature, a trained health professional was considered an appropriate person to serve as a facilitator of the group process, particularly giving more guidance and assistance in the early stage of group development (Powell, 1994).

The 3-day training workshop conducted for the group facilitator in this study would be useful as a reference for other nurses and health professionals who plan to work as facilitators of family support groups for mental illness. The contents of the workshop were largely derived from the practical experience and guidelines reported by Atkinson and Coia (1995), Westberg and Jason (1996) and Gazda, Ginter and Horne (2001). The workshop provided important and essential information, techniques and principles about the establishment, facilitation and evaluation of a mutual support group, via critiques of videotapes about simulated family group meetings, mini lectures to elicit information about the family support group planned by the researcher, and discussions on principles, guidelines and checklists for working with a family support group. The main themes and content of the workshop are summarised as follows:

Day 1: Understanding the mutual support group and your attitude to group work:

- This first day of the workshop was mainly focused on an introduction to the mutual support group and its key elements and the recognition and clarification of the facilitator's values and attitude to the future group work.

Day 2: Learning from group experience and establishing techniques in facilitation of a mutual support group:

- A video about how to talk to families of patients with schizophrenia was shown and discussion was then made to understand the importance of being knowledgeable and skilful in communicating with a single family and families in groups.
- In the afternoon, the facilitator participated in and observed a 1-hour meeting of an existing family support group conducted by a community psychiatric nurse at an outpatient clinic. The facilitator discussed with the community nurse and two members of the group the important issues concerning the process and interaction skills observed during the meeting.

Day 3: Advanced skills of group facilitation, practice of family interview and review of learning to be a facilitator:

- An experienced group therapist was invited again to teach some advanced skills in facilitation of a family group such as the techniques for encouraging group members to actively involve and attend the group and the ways to offer support, advice, information, resources, and referrals to group members.
- A discussion was carried out to appreciate the importance of confidentiality, when and how to achieve this, and how to recognise various dilemmas and difficulties.
- A review of the learning objectives of this workshop for the group facilitator.
- The methods and procedures of pre-test and post-test measurements in this study were introduced by the researcher, so that the facilitator could have more understanding about the data collection process.
- The facilitator practiced a telephone contact and a face-to-face interview with one family member of a patient with schizophrenia. An evaluation of the performance was done immediately after the practice.

Post-workshop practice and supervision

- After the workshop, practice of group facilitation with a family group and telephone interview technique was arranged for the facilitator in order to ascertain and evaluate his learned skills of group facilitation and follow-up of families in-between group meetings.
- Continuous supervision comprised consistent reviews of the audiotape of each session of the support group in the pilot study by the researcher, one family therapist and the facilitator and regular clarification of the issues arising in-between group meetings.

One or two active and sociable members within the group, who were identified by the facilitator under the consensus of the whole group, helped co-ordinate the group and lead discussions during the group meetings. Practical assistance, advice and resources were given by the researcher and facilitator to the peer leaders and other group members, such as arranging meeting venues and providing equipment, development of information resources and discussion summary, and seeking consultation from or referral to health care services if needed.

4.4 ROLE OF THE NURSE AS A GROUP FACILITATOR

Recent studies of mutual support groups have reported that success in any programme correlates with more intense mutual help involvement (Lieberman &

Snowden, 1994; Kessler, Mickelson & Zhao, 1997). Therefore, it was very important for the group facilitator and peer leader(s) to encourage the group participants to be as actively involved in the group as possible. As suggested by Kurtz (1997) and Steinberg (1997), although using different labels for the therapeutic endeavours in the literature, the role of the facilitator (psychiatric nurse) in this mutual support group included:

a. Encouraging and modelling information giving and sharing, while relating this process to goals of building trust and a caring context;
b. Eliciting, and if necessary, mediating differing opinions, while pointing out the group's ability to build individuality within group solidarity;
c. Giving advice to discuss taboo areas, while strengthening the group's commitment to confidentiality and safety;
d. Insisting firmly that the need for lifestyle change includes finding a new support system;
e. Calling attention to members' shared situations, thus emphasising the common bond;
f. Reinforcing and demonstrating empathic responses, with the intention of building mutual support and not blaming or indicting families or patients for the problems;
g. Supporting mutual demands, while validating the expectations for all members to work;
h. Allowing individual problem solving to take place, while helping group members assume consultant roles in dealing with stress, emotional upset and burden; and
i. Engaging members in rehearsal of behaviour, giving the message that risk-taking is safe.

The group facilitator also allowed the peer leader(s) to take on some of these functions, if able to do so, in order to enhance the mutual helping and support atmosphere within the group. The facilitator should be careful not to take over the peer helper role from the peer leader or other group participants. Instead of being dependent on the facilitator, the participants should be assisted to find peers who could help them achieve a life of continuing growth through the group intervention (Kyrouz, Humphrey & Loomis, 2002). Nevertheless, the facilitator sought to remain available to the group members if something emotionally and psychologically negative or harmful happened. It was important to recognize and resolve any harm experienced by individual members, which was often related to destructive group dynamics, if a family caregiver was rejected by other group members or felt they had nothing to offer or gain from the group.

4.5 ROLE OF PEER-PARTICIPANT LEADER/FACILITATOR

The fundamental task of the mutual support group was to develop a mutual aid system, led or facilitated by one or more group members who had a commitment to the belief that people can help one another, a sensitivity to the group's phases and processes, and skill in utilizing support building techniques. Although the leading or facilitating work of the peer leaders might not be acknowledged and formalised as a 'leader' position, their informal role of coordination and facilitation of the group intervention was considered very important. During the intervention, these informal group leaders were able to (Powell, 1994; Galinsky & Schopler, 1995):

a. Assist and encourage the group to be more transparent and more apt to engage in self-disclosure (however the facilitator will also engage in this self-disclosure);
b. Accentuate socially approved behaviour through positive reinforcement and encouragement (i.e. focusing on supportive rather than interpretative issues of members);
c. Encourage increased control and the helping function among group members;
d. Provide some guidance and information when group members cannot find the resources (however, the group should be given adequate opportunity to find out the information or resources by themselves first);
e. Reinforce interdependence by pointing out the similarities and differences between members, in the services of increased group cohesion; and
f. Act as a role model to nourish an attitude of trust and confidence in participants.

4.6 GROUP PHASES

In discussing theories of small-sized group intervention, the concept of progressive phases generally arises when exploring the pattern of group development. Throughout the phases of group development as well as establishment of interpersonal relationships, group members perform a variety of roles, mainly group building, group maintenance, task, and individual roles, and thus share the power of self-determination, information and skills exchange, group dynamic and participative management (Yalom, 1995; Sampson & Murtha, 1997). Indeed, groups have a natural history of development; the five phases of group development used in the mutual support group intervention were the generally accepted ones of groups in the literature of health, social and behavioural sciences (Cragan & Wright, 1999). The use of this phased development in the mutual support group was preferred to the identification of definite

tasks or topics for each group session; on the other hand this allowed flexibility in time, task achievement, development of trust, autonomy, closeness, interdependence, and termination of the group (Akinson & Coia, 1995; Wilson, 1995). The group and its members themselves could have more control in the group development, although the facilitator and/or the peer leader(s) needed to assist in the smooth and efficient progression of group functions and achievement.

However in each group phase, the group facilitator and/or peer leader(s) made a great effort to maintain telephone contact with each individual group member weekly and encouraged each member to attend the next meeting. When any members of the group found difficulty in attending a group session, the facilitator was responsible for raising these issues in the group meeting and ensuring the group participants negotiated a mutually agreed time and venue of the meeting.

Similar to other phase theories in support groups, Wheelan (1994) and Kimberly (1997) delineated the group development in terms of at least five stages, which were incorporated into the 12-session mutual support group intervention used in this study, as described in detail in Table 4.2. The five phases of the group intervention are listed below. The number of sessions cited in the parentheses was tentative and subjected to change in accordance with the group progress and the mutual agreement among the family carers.

- Phase 1 - Engagement (Session 1 – 2)
- Phase 2 - Recognition of psychological needs (Session 3 – 5)
- Phase 3 - Dealing with psychosocial needs of self and family (Session 6 – 8)
- Phase 4 - Adopting new roles and challenges (Session 9 – 11)
- Phase 5 – Ending (Session 12)

In order to increase understanding about the phased development of the group, the five phases of the mutual support group are explained in more detail in Appendix 4. Through this delineation, the researcher intended to present a more precise protocol and structure of the support group intervention, which might assist the evaluation of the effectiveness and replication of the group intervention.

Table 4.2 Mutual Support Group Programme for Family Carers of A Relative with Schizophrenia

Phase/Stage	Theme	Content	Format of sessions	Length of intervention*
1. Engagement (Introduction)	Who we are; We need to share our experiences and feelings *Goal:* Establishing trust relationship and common goals	• Orientation of the group programme (format, duration, content, flexibility, and so forth) • Introduction of the overall purposes of the group intervention and expectations of each participant; • Beginning of sharing common concerns and establishing trust and acceptance; ensuring confidentiality; • Negotiation of goals/objectives, rules and norms, and roles and responsibilities; • Recognising and clarifying the role of a facilitator in the group; • Initial discussion of the patients' mental illness, symptoms, behaviours, and their effects on family.	• Briefing by facilitator • Discussion among group participants • Video show about schizophrenia and followed with discussion	2 sessions *1st session* *2nd session (optional to include patient)*
2. Recognition of psychological needs	Being aware of and accepting our feelings and reactions *Goal:* Open sharing and more understanding about individual concerns and cultural issues	• Resolution around power, control and decision making within group; any need of a peer leader; • Discussion about Chinese culture of their family (e.g. family structure, relationships and communication patterns) and attitude towards mental illness • Clarifying information and misconceptions by them (and other family members) about schizophrenia and its related illness behaviour; • Exploring and verbalising the intense emotions and feelings about the difficulties in patient care provision and family interactions; sharing stories of success and difficulties in living and interacting with patient;	• Discussion • Explanation with leaflet • Discussion with scenarios presented by participants • Discussion and sharing and role modelling by one or two more experienced family carers	3 sessions *3rd session* *4th session*

		• Discuss about the ways to deal with negative feelings and emotions to patient; • Encouraging members to face powerlessness and limitations and accepting the 'self-as-is' • Focusing and paying specific attention to: (a) helping members to view themselves as 'average' or 'similar as others' among the group members, not exceptional; and (b) reduction of participants' exaggerated or dysfunctional sense of shame, by sharing and recognising unrealistic self-expectation, expectation to patient, and externally imposed evaluations.	• Discussion about their expectations and reaction toward social stigma and pressure.	*5th session*
3. Dealing with psychosocial needs of self and family	Understanding about our relative's needs and available community supporting resources Goal: Adequate understanding about important needs for self, patient and family	• Discussion about each participant's physical and psychosocial health needs (how they relate to family culture); • Information about medications, management of the illness, and available mental health services for patient and family; • Learning and practice for effective communication skills with patient; seeking social support from others e.g. family members and friends; • Exploration of appropriate home management strategies e.g. finance and budgets, social support network, living environment and hygiene.	• Self-reporting and discussion • Explanation and information leaflet • Demonstration, role play, and giving principles • Discussion and sharing experience	3 sessions *6th session* (optional to include patient) *7th session* *8th session*

4. Adopting new roles and challenges	Recognising and adapting to new roles and challenges in caregviing *Goal:* Learning from other participants the effective coping skills and management of patient with schizophrenia	• Sharing their coping skills for demands of care, family dysfunctions and conflicts, and their positive things/experience with patient; • Identifying the supporting persons to their burden of care in their social environment; • Enhancing problem solving skills in caregiving and minimising family conflicts and burden, by working on some individual patient management situations; • Conducting behavioural rehearsals of interactions with patient and other family members within group; • Practicing coping skills learned during the sessions to real family life (in-between group sessions) and evaluate the results; • Re-evaluating their family role and responsibility and shared responsibility of caregiving among family members	• Discussion • Explanation, case study, and discussion • Role play • Home assignment and evaluation • Discussion	3 sessions 9^{th} session *10^{th} session* *11^{th} session*
5. Ending	Conclusions – Where will I go from here? *Goal:* Preparing for group termination or continuation	• Preparation and discussion on termination issues e.g. separation anxiety, independent living and use of coping skills learned; • Evaluation of learning experiences and goals achievement; • Discussion about the continuity of care after this group programme and the utilisation of community supporting resources; • Explanation of post-intervention assessment and follow-up taken in the following months.	• Discussion	1 session *12^{th} session*

Note. * A total of 24-week group intervention was carried out, on a bi-weekly basis. Achievement of the content and themes was reviewed following each group session by the facilitator and researcher.
Two major amendments were made on the mutual support group programme used in the main study, in response to the comments by the expert panel and group participants in the pilot testing: (a) There would be one session added to the fourth group phase (adopting new roles and challenges), thus consisting of four sessions; and one session was deducted from the second phase (recognition of psychological needs) and thus became two sessions; and (b) one extra session was conducted for those who were interested in group continuation to discuss for detail arrangement.

4.7 PILOT TESTING OF THE MUTUAL SUPPORT GROUP PROGRAMME

A pilot study was conducted from March to December 2002 to test the support group intervention protocol and procedure, group facilitation skills training, questionnaire use and data collection procedure. This pilot investigation was essential to ensure better preparation and thus increase the fidelity and validity of the main study. The pilot study consisted of two phases. Phase 2, which comprised an experimental study to examine the structure and process of a mutual support group intervention, its feasibility and the intervention protocol, and to test for its immediate effects on family carers (and the perceived benefits and difficulties in participating in the 3-month mutual support group), is described in Appendix 6 (The pilot study was published in an international refereed nursing journal by Chien, Norman and Thompson in 2004). A total of 48 families were selected randomly from the 185 families of the patients with schizophrenia from one regional psychiatric outpatient clinic in Hong Kong (i.e. the same as the convenience sample of Phase 1 of the pilot study), after they had completed the questionnaire, consisting of the families' and patients' outcome measures used in the Phase 1 of the pilot study, and in the main study. Then, they were allocated randomly to an experimental (mutual support) group (n=24), or a control group (n=24) receiving conventional family services. The family and patient-related outcome measures were the same as those which would be used in the main study. Therefore, the findings indicated important issues about the support group programme and recommendations could be made to improve the group programme used in the main study (see Section 4.8). However, Phase 1 of the pilot investigation comprised a descriptive survey of Chinese families caring for a relative with schizophrenia in Hong Kong, conducted primarily to test the key instruments for test-retest and inter-rater reliability, and validity prior to use in the main study and is described in Chapter 5.

Prior to the pilot testing of the effectiveness of the mutual support group programme, an expert panel, consisting of 10 mental health professionals who were experienced in psychiatric rehabilitation, examined content validity of the group programme. The effectiveness of the mutual support group intervention was established by testing the null hypotheses that there would be no significant difference in specified patient and family outcomes (i.e. similar to those used in the main study; see Appendix 6) between families who participated in the mutual support group and controls who only received the conventional psychiatric outpatient service.

4.7.1 Content validity of the programme

Ten experts in psychiatric rehabilitation (two psychiatrists, two clinical psychologists, two community psychiatric nurses, three nurse specialists in psychiatric rehabilitation and one medical social worker) were invited to comment on the appropriateness of the content and arrangement of the programme and independently rated the relevancy of the themes, goals and main contents of the mutual support group programme on a 4-point rating scale. They rated the relevancy of each item as: 1 = not relevant, 2 = somewhat relevant, 3 = relevant, and 4 = very relevant. Content validity of the programme was estimated by calculation of a Content of Validity Index (CVI), which indicated the extent of agreement between the 10 experts. The CVI, representing the proportion of items that received a 3 or 4 rating of the 4-point rating scale used by the panel members, indicates acceptable level of validity when it is more than 0.85 (Waltz, Strickland, & Lenz, 2005).

According to the expert panel review, the CVI of the overall programme was 93% with all items ranging from 80% - 100%, indicating that the contents of the support group programme were acceptable and appropriate, and thus it was considered to demonstrate a satisfactory content validity. Only one item, "Focusing and paying specific attention to: (a) helping members to view themselves as 'average' or 'similar as others' among the group members, not exceptional; and (b) reduction of participants' exaggerated or dysfunctional sense of shame, by sharing and recognising unrealistic self-expectation, expectation to patient, and externally imposed evaluations" in "Stage 2 – Recognition of psychological needs", were deemed by two raters (20%) as unclear and too complex in meaning and unable to judge the relevance. The item was amended and simplified to: "Focusing on helping the families to: (a) recognise their similarities in situations concerning caregiving with other group members and that they are not isolated or exceptional; and (b) reduce their exaggerated feelings of shame, self-blame, and unrealistic expectations to themselves and the patients in caregiving." In addition, in response to the comments from the expert panel and the group participants (individual interview following the intervention), one extra session was conducted for those group participants who were interested in planning for their future and for the potential group continuation to discuss arrangements.

4.8 CHANGES TO THE MUTUAL SUPPORT GROUP PROGRAMME IN THE LIGHT OF FINDINGS OF THE PILOT STUDY

The findings of the pilot testing of the group programmes highlighted some important issues to be considered for implementation of the group intervention in the main study described in Chapter 6 ('Methods of the Main Study'). These included:

4.8.1 Changes arising from testing content validity and trial run of the group programme

The content validity of the mutual support group programme was found satisfactory and the expert panel suggested only a few minor amendments. In response to the comments from the expert panel and the group participants (individual interview following the intervention), one session was added to the fourth group phase (adopting new roles and challenges), which would become four sessions when used in the main study; and on the other hand, one session was deducted from the second phase (recognition of psychological needs) and thus it consisted of two sessions. In addition, one extra session would be conducted for those group participants who were interested in planning for their future and the potential group continuation to discuss for detail arrangements.

However, to ensure consistency, fidelity control and validity of the group intervention, regular reviews were made of the audio-tapes of group sessions by the researcher with the group facilitator following each group meeting; adherence to the key principles of the group intervention and the themes of the group sessions would be monitored using a simple checklist, and those not found in each session would be discussed and reinforced in the coming session. Regular discussions about the group progress and difficulties encountered would be made on a bi-weekly basis before the coming group session, between the researcher and group facilitator, in order to resolve problems and to clarify issues about the group process and facilitation.

During the six-month intervention, bi-weekly telephone follow-up would be conducted by the group facilitator to encourage the family carers to attend the group sessions and collect data on families and patients' conditions such as family conflicts and health care services received during that period. As part of the intervention, the facilitator answered questions from the group participants and made referrals to supporting services, if needed. During the 12-months follow-up, the facilitator, would

also conduct monthly telephone contact in order to collect participants' outcome data and also to minimise their attrition from the study,

Last, in the trial run, the mutual support group was found to have effects on the primary and some secondary outcomes. These included a significant reduction of family burden of care, and increased family functioning and satisfaction with social support. However, the other family and patient outcomes did not differ between the experimental and control groups. This may be explained by the fact that the mutual support group could only exert a progressive effect on patients' re-hospitalisations and family activities and conflicts during intervention and thus indicated only modest positive results in average over the six-month period of the group intervention. In addition, the pilot study was conducted in a single psychiatric clinic with a small sample size, which could limit the internal validity and generalisation of the study results. Therefore, in the main study, a larger sample would be recruited from two of the largest psychiatric outpatient clinics in Hong Kong and, also, a longer period of follow-up (12 months) after the mutual support group would be conducted to identify the substantial effects of the intervention compared with usual outpatient care.

4.8.2 Potential obstacles to group development and contingency plans

The findings of the pilot testing of the mutual support group programme highlighted a few potential obstacles to group development, which would be considered in the main study. The group facilitator and the group members set out to build mutual support and should be cognizant of the potential obstacles for mutual aid, which might exist in the group. On the other hand, the group facilitator and researcher should be aware of over-identifying with the family carers' resistance to attending the group meetings. They should help and encourage them to find an adequate and effective social support system, and thus better cope with their caregiving role (Buchkremer et al., 1995). The anticipated problems and pitfalls in working with the mutual support group identified from the pilot study, and similar support group studies and experiences (Nichols & Jenkinson, 1991; Borkman, 1999; Westberg & Jason, 1996), are discussed as follows.

An irregular or low attendance by group members

It has been commonly but inappropriately accepted that attendance of a social or therapeutic group may be poor. There are various reasons for poor attendance, and

people with low attendance can be more difficult to integrate into the mutual-aid social world. Problems such as difficulties with transport and inconvenient meeting venue and other barriers to attendance need to be carefully considered and resolved. Difficulties due to low attendance were also encountered and discussed by the family carers with low group attendance in the pilot study, such as: "building a more trusting relationship and an intimate and open social climate", "achievement of common goals and contracts", and "positive behavioural changes and effective coping skills for caregiving" (refer to Appendix 6). Therefore, more attention needs to be paid to encouraging regular and continued attendance of group members, in particular ensuring flexibility of time of group meetings with regular contact of group members and encouragement of group participation, not only from the facilitator but also from the more enthusiastic group members (Luke, Roberts & Rappaport, 1993).

Difficulty of inexperienced or young carers in establishing relationships

When starting the group, there might be a few young or inexperienced caregivers who find it difficult to express their own concerns and needs on caregiving or identify with the troubles and suffering of other group members (i.e., inability to form caring relationships). More help and support should be directed to these members in the first and second meetings with the more experienced caregivers discussing their caring experiences, both successful and failed). The inexperienced caregivers would then be more confident and willing to share their views and experiences following the shared experiences of the experienced caregivers.

A general failure concerning group development

Certain rules and roles within the group operated in ways that prevented any sustained cooperative efforts. For example, certain un-stated rules such as what may or may not be talked about within the support group obviously were in opposition to the value of openness among group members. Therefore there needs to be more flexibility in allowing personal interests and issues to be talked about during the group meetings. More tasks and activities should be done collaboratively among group members, instead of being a single member's work.

Difficulty in establishing the norm of open and honest communication

An open and honest communication was a good working culture for the group. However, some of the group members might find it embarrassing and uncomfortable

to expose some personal, unpleasant events or the harmful or painful consequences for which they were responsible. They needed much more time and encouragement to open up themselves to the others. It was also essential to have some active group members' mutual sharing and concern, which was considered one of the key elements for these embarrassment and suspicions to diminish.

4.9 CONCLUSION

In summary, the feasibility of the method and process of mutual support group intervention and the facilitator training workshop was examined in Phase 2 of the pilot study and a trial run of the family support group was conducted with positive results. The mutual support group programme was found to have effects on the primary and some secondary outcomes. These included a significant reduction in family burden of care, and increased family functioning and satisfaction with social support. The null hypotheses, that there would be no significant differences in family outcomes for families that participated in a mutual support group compared with those in receipt of conventional psychiatric outpatient services, were rejected. The eta squared statistics for family burden and SSQ6– Level of Satisfaction score using the ANCOVA were 0.68 and 0.70 respectively, indicating large effect sizes. However, the effects on the patients although positive, were non-significant between the experimental and control group with respect to improvements in their specific level of functioning and length of hospital stay. These findings warrant further investigation of the effectiveness of mutual support group intervention for the family carers with a larger sample size of patients and their families in the main study. They also alerted the researcher to amendments required in the design of the main study.

In addition the pilot study identified some preliminary themes and factors influencing the therapeutic process and possibly the effectiveness of a mutual support group intervention for the family carers, through content analysis of the transcripts of the group meeting and semi-structured interview data. These themes and related categories included: the individual changes of group members (changes in personal identity, changes in perception of mental illness and adoption of new coping skills for caregiving), positive and negative group characteristics (group ideology and consensus, social climate in relation to task orientation, empowerment, and inhibitory factors influencing group development), and influences of external environment on the group (perceptions of professional involvement and support and support from family

members and close relatives outside group). These themes and categories provide a valuable basis for development in hypotheses about which aspects or ingredients of the group intervention will have most effects on families, and thus should be investigated further in the main study.

CHAPTER 5 PILOT TESTING THE RELIABILITY AND VALIDITY OF OUTCOME MEASURES

5.1 INTRODUCTION

This Chapter reports the design, methods and findings of Phase 1 of the two-phase pilot study on the research instruments used as outcome measures in the main study. Phase 2 of the pilot study (described in Chapter 4) comprised an experimental study to examine the structure and process of the mutual support group intervention, its feasibility, the intervention protocol, and to test for its immediate effects for a small group of family carers of patients with schizophrenia in one outpatient clinic. Phase 1 of the pilot study was conducted from March to May 2002 and comprised a descriptive survey of Chinese families caring for a relative with schizophrenia in a major geographical region of Hong Kong. It aimed primarily to test the key outcome measures to be used in the main study for test-retest, inter-rater reliability and internal consistency, and validity - specifically content validity and semantic equivalence. The aim and objectives of Phase 1 of the pilot study and the methods used are presented in Sections 5.2 and 5.3. Translation and validation of the primary outcome measure, Family Burden Interview Schedule (FBIS), are presented in Section 5.4. The results of testing the reliability and validity of the FBIS and four other research instruments and the relationship between scores on the five instruments, drawn from a survey of 185 Chinese families of outpatients with schizophrenia, are then described (Section 5.5). The psychometric properties of the instruments are summarised in Section 5.6.

5.2 AIMS AND OBJECTIVES OF PHASE 1 OF THE PILOT STUDY

The aim of Phase 1 of the pilot investigation was to establish the reliability and validity of the key instruments, which were to be used in the main study. The objectives of this phase of the pilot study were to:

1. Establish the reliability and validity of the primary outcome measure, a Chinese version of the Family Burden Interview Schedule (FBIS), specifically to assess the measure for test-retest reliability, inter-rater reliability, internal consistency, content validity and semantic equivalence with the original English version;
2. Establish the test-retest and inter-rater reliability of the other four research instruments (Family Assessment Device, Six-item Social Support Questionnaire,

Specific Level of Functioning, and Family Support Services Index), which were to be used as outcome measures in the main study;

3. Describe the psychosocial health status of families caring for a patient with schizophrenia (duration of illness not more than five years), and the patients themselves, in one major geographical region of Hong Kong;
4. Describe the relationship between the socio-demographic characteristics of the subjects and their psychosocial functioning.

5.3 METHOD

The first phase of the pilot study described in this chapter was concerned primarily with testing instruments designed to measure the psychosocial health status of patients with schizophrenia and their family carers. These instruments were the key research tools to measure the family and patient outcomes, specifically targeted for examining the effects of the mutual support group programme for family carers used in the main study. The study design, sampling method, data collection procedure, and data analysis strategies of the pilot study are described below.

5.3.1 Study design

A cross-sectional descriptive survey using face-to-face administration of questionnaires was chosen to achieve the objectives of this pilot investigation listed in Section 5.2. This design was considered appropriate given that the use of a highly structured questionnaire in a face-to-face interview is considered effective for ensuring high response rate and adequate understanding of the questions being asked, in particular when the questionnaire is lengthy or complex (Portney & Watkins, 2000). However, the interviewer should have sufficient understanding about the instruments and their instructions to respondents and skills of administration of the questionnaire, to ensure that the reliability of responses is not compromised. Therefore, the researcher, who was the person most familiar with the research instruments, acted as the interviewer in this study. Moreover, a structured questionnaire is a simple and direct measure to obtain respondents' perceptions of their health status and functioning. It also allows the researcher to identify, compare and explain health needs in relation to the characteristics of specific informant groups, which was an important function of the survey design (Fink, 1995). In this study, the use of a set of structured questionnaires or research instruments by the researcher was found to be

most feasible and economical in terms of time and resources, to examine a variety of psychosocial outcomes of the family carers and their patients at the four different times of measurement (baseline and three post-tests).

5.3.2 Sample and research sites

The subjects targeted for this pilot investigation were 250 Chinese families caring for a relative with schizophrenia from one regional psychiatric outpatient clinic in the New Territories, the largest geographical region in Hong Kong. This sample size was adequate for a valid testing of the factor structure of the 25-item FBIS (i.e. at least 10 subjects per item for exploratory factor analysis of a research instrument as suggested by Stevens, 2002). They were selected randomly from the patient lists of the outpatient clinic and its community psychiatric nursing service (CPNS), using a list of computer-generated random numbers. They were also checked against the inclusion and exclusion criteria of subjects listed below for ensuring eligibility for participation in this study. Data collection was conducted over two months, between April and May 2002.

There were in total about 500 outpatients diagnosed with schizophrenia and without co-morbidity of another mental disorder, who fitted the inclusion criteria specified below, and who were receiving follow-up treatment at the outpatient clinic under study. This number of patients represented approximately 10% of the total number of outpatients with schizophrenia in Hong Kong (Hospital Authority Hong Kong, 2002). Half of the patient population (n=250) was randomly selected for this study and according to Levy (1991), this sample size allowed a ± 0.05 sampling error with 95% confidence level and population-proportion estimates of p=0.50. This target sample size was also sufficient to detect any significant correlations between variables within the subject group with a medium effect size at power 0.90 for the level of significance set at 0.05 (Cohen, 1992).

Inclusion criteria of subjects were family members who:

- Lived with and cared for one relative with a primary diagnosis of schizophrenia according to the criteria of the Diagnostic and Statistical Manual of Mental Disorders, 4th edition [DSM-IV] (American Psychiatric Association, 1994);
- Cared for a relative with schizophrenia who suffered no co-morbidity of another mental illness during recruitment to the study and who had been diagnosed with schizophrenia for not more than five years;

- Were aged at least 18 years and could speak and understand Mandarin or Cantonese;
- Were free from any psychiatric disorder themselves; and
- Agreed voluntarily to participate in the study.

Families were excluded from the study if they cared for more than one family member with mental illness or chronic physical disease, were the primary carer for less than three months, or suffered from mental or organic brain disorder themselves.

5.3.3 Recruitment and randomisation

A list of patients with schizophrenia attending follow-up at the outpatient clinic under study were retrieved from the computerized patient information system of the clinic and checked against the study criteria in Section 5.3.2. Eligible patients were numbered in alphabetical order and the list of patients was kept in the office of the researcher. Patients for inclusion in the study were selected on the basis of 250 random numbers generated by the researcher using a random numbers table. The researcher approached the randomly selected patients in person during follow-up appointment to seek written consent for voluntary participation in this study and their permission to approach their family members. With the patients' permission, one member of each family who was the primary carer of the patient was contacted via phone to explain about the purpose and procedure of the study and invite his/her participation in the study. With written consent in another face-to-face interview, there were finally 185 families willing to participate in the study. This final sample size was able to detect any significant correlations between variables within the subject group with a medium effect size at power 0.80 for the level of significance set at 0.05 (Cohen, 1992).

5.3.4 Ethical considerations and data collection

Ethical approvals were obtained from the psychiatric outpatient clinic and the Clinical Research Ethical Committee, Faculty of Medicine at the Chinese University of Hong Kong (i.e. a copy of the approval letter from the Ethics Committee in Appendix 12). Data were collected over a period of two months from the outpatient clinic. Eligible patients with schizophrenia were invited to participate in the study by the researcher during their follow-up consultation at the clinic. They were fully informed of the purpose of the study, what would be expected of them as participants, possible benefits and risks of study subjects, and their right to terminate participation at any time. Subjects and

clinic staff were also assured that all data referring to the trial were kept in a data file accessible to the researcher only and that the personal identity of the subjects or clinic would not be revealed in any research report or documentation.

With patients' written consent, one of their family members suggested by the patients to be the primary carer, who also met the study criteria, would be approached in person to obtain written consent as subjects, with full explanation of the study. Families were also asked to consent to participate in the clinical trial in Phase 2. With families' written consent, the researcher administered the research instruments to each of the primary carers individually in one of the interview rooms at the clinic. To investigate the test-retest reliability of the FBIS, the instrument was administered again to the families at two-week intervals.

5.3.5 Research instruments

A structured questionnaire comprised the Chinese version of five measurement scales and a demographic data sheet. The five measurement scales included a Chinese version of the Family Burden Interview Schedule (FBIS; Chien & Norman, 2004), Family Assessment Device (FAD; Sun & Cheung, 1997, modified from the McMaster Family Assessment Device by Epstein, Baldwin & Bishop, 1983), Six-item Social Support Questionnaire (SSQ6; Chang, 1999), Family Support Services Index (Heller & Factor, 1991), and Specific Level of Functioning scale (SLOF; Lee, 1999). The English versions of the five instruments are attached in Appendix 7. The questionnaire required about 30 to 40 minutes to complete. It was also used for pre-test and post-test outcome measures and the socio-demographic information of both the experimental and the control groups in Phase 2 of the pilot investigation and the main study, with additional family and patient outcome measures such as family conflicts and patients' re-hospitalisations. Details of the measures are described as follows:

The Family Burden Interview Schedule (FBIS) is a 25-item semi-structured interview schedule designed by Pai and Kapur (1981) to assess the burden of care experienced by families of a patient with schizophrenia living in the community. It consists of six domains of perceived burden (2-6 items in each domain), including effects on family finance, routine, leisure, interactions, physical health and mental health. The items are rated on a three-point Likert scale ('0'- 'No burden', '1' - Moderate burden' and '2' - 'Severe burden'); and remarks were given for explanation of the difficulties felt by the respondents on any of these items. An overall evaluation of family

caregiving burden could be made by asking a standard question: 'How much would you say you have suffered owing to the patient's illness?' and scoring on the same Likert scale. The total scores range from 0 to 50, with a higher score indicating higher burden of care. Inter-rater reliability for items reported by Pai and Kapur (1981) ranged from 0.87 to 0.99; and were 0.78 and 0.72 for total scores rated by health professionals and families, respectively. Significant correlations with both clinical psychopathology and social dysfunction in the patient were demonstrated (Pai & Kapur, 1982). Since there was no Chinese version available, translation of the original FBIS to a Chinese version and testing content validity and semantic equivalence of the Chinese version were conducted (described in Section 5.4) before testing its factor structure and the reliabilities of all the instruments used in the descriptive survey.

The Family Assessment Device (FAD) developed by Epstein, Baldwin and Bishop (1983) was used to assess multiple dimensions of family functioning among patients with mental disorders and other chronic diseases, and was based on a well-developed theoretical and family treatment model. It consists of 60 items to measure family functioning on a 4-point Likert type scale (from 1- 'strongly disagree' to 4- 'strongly agree') along seven dimensions: problem solving, communication, roles, affective responsiveness, affective involvement, behavioural control, and general functioning. The FAD demonstrated high internal consistency and inter-rater reliability, and minimal social desirability effects (Keitner et al., 1990). The Chinese version of the FAD demonstrated adequate content validity, high inter-rater reliability (ICC for overall scale was 0.85) and minimal social desirability effects in Chinese people with schizophrenia (Sun & Cheung, 1997). Sun and Cheung (1997) also reported that the Cronbach's alpha coefficient was 0.97 for overall scale and ranged from 0.68 to 0.92 for subscales. The total scores range from 4 to 28, a higher score reflecting poorer family functioning.

The Six-item Social Support Questionnaire (SSQ6) was used to determine how many people supported each family caregiver, as well as the caregivers' satisfaction with the support they received. This six-item short version questionnaire was developed by Sarason et al. (1987) from the original 27-item Social Support Questionnaire (Sarason et al., 1983), in recognition of the need for rapid assessment of this construct in clinical setting. Respondents were first required to indicate the number of supporting persons (i.e. Number score) they had and then to provide a rating of their overall satisfaction with the support (i.e. Satisfaction score) provided by

all the persons identified, using a six-point Likert scale (1 - 'very dissatisfied' to 6 - 'very satisfied'). The SSQ6 indicated high internal consistencies of 0.9 for Number score and 0.93 for Satisfaction score (Sarason et al., 1987). It was translated to Chinese language by Chang (1999) and Cronbach's alpha of the scale was 0.94 and weighted kappas ranged from 0.48 to 0.67, indicating a satisfactory level of item equivalence between the two versions. The intra-class correlation coefficient (ICC) was 0.88, indicating high correlation between both versions.

The Family Support Services Index (FSSI) is a checklist developed by Heller and Factor (1991) to measure the formal support service needs and their usage by patients with mental illness and their families. It was translated into Chinese language according to the available family support services for mentally ill people in Hong Kong, using the service list obtained from community psychiatric nurses and medical social workers. An expert panel of 5 health professionals, including two community psychiatric nurses and medical social workers and one registered psychiatric nurse, reviewed and agreed with the comprehensiveness of the list and the translation, except two items (i.e. in-home & out-of-home respite services) which were not appropriate to the local situation. Thus, these two items were deleted after consultation with the panel. The modified index contains 16 items of family supporting services and each item is rated for whether family is in need of it (Yes/No) and whether they are receiving (Yes/No). Inter-rater and internal reliabilities were 0.88 and 0.84 respectively, when administered to 192 Chinese family carers of patients with schizophrenia in Hong Kong (Chien & Norman, 2003). The responses to this scale indicate the number of services that families would like to have and that they are in need of but not receiving.

The Specific Level of Functioning Scale (SLOF) was a 43-item assessment scale developed by Schneider and Struening (1983) and modified by the Division of Mental Health Services in the State of New Jersey, in the United States (Miller et al., 1985). It comprises three functional areas of patients with schizophrenia, including self-maintenance (12 items, covering physical functioning and personal care skills), social functioning (14 items, covering interpersonal relationships and social acceptability) and community living skills (17 items, covering activities of daily living and work skills). The items were rated by family members in a face-to-face interview with the researcher. Face validity was established and reliability testing was satisfactory for Hong Kong Chinese patients (Lee, 1999). In Lee's (1999) study, the Cronbach's alpha coefficient ranged from 0.94 to 0.96 for the

subscales, and was 0.88 for the overall scale. Satisfactory test-retest reliability (r= 0.76) was reported. Inter-rater reliability between family members and professional raters was 0.79, indicating a satisfactory consistency of ratings between two independent raters.

Family carers also completed the demographic data sheet attached to the questionnaire, which included their age, gender, educational level, biological relationship with patient, monthly household income, number of family members living with patient; and the patient's age, gender, duration of mental illness, present medication, and mental condition (improved, stable/staying the same, or worsened/not stable) in the last three months.

5.3.6 Data analysis procedures

Descriptive and inferential statistics were employed on the data in the questionnaire and the demographic data sheet, using the Statistical Package for Social Sciences (SPSS) for Windows version 12.0. The data analysis strategies for this study are summarised in Table 5.1.

Table 5.1 Strategies for analysis of data from Phase 1 of the pilot testing

Purpose/hypothesis	Variables	Instrument/method	Statistical tests
To describe families and patients' characteristics and the psychosocial health status of these families. (Refer to Objectives 3 and 4 in Section 5.2)	• Family carers' age, monthly household income, number of family members living with patient; • Patients' age and duration of mental illness • Families' FBIS, FAD, SSQ6, and FSSI scores and patients' SLOF scores; (interval or ratio data)	Demographic data sheet	Means, standard deviations, ranges (minimum and maximum values)
	• Family carers' gender, education level, biological relationship with patient; • Patients' gender, present medication and mental condition in last 3 months (ordinal or nominal data)	Demographic data sheet	Frequencies and percentages

There are no statistical significant differences in selected demographic characteristics between the sample and the parent population. (Refer to Objective 4 in Section 5.2)	• Families' monthly household income • Patients' gender, age range, educational level, number of family members living with patient, present medication dosage, and duration of illness	Demographic data sheet and the Annual Statistical Report from the Hospital Authority, Hong Kong (2002)	Goodness of fit Chi-square test
To examine the internal consistency and inter-rater reliability of the five measurement scales. (Refer to Objectives 1 and 2 in Section 5.2)	• Item and scale mean scores of the five psychosocial measures – FBIS, FAD, SSQ6, FSSI, and SLOF	Questionnaire consisting of the FBIS, FAD, SSQ6, FSSI, and SLOF	• Cronbach's alpha coefficients of overall scales and subscales • Intra-class correlation coefficient
To examine the test-retest reliability and construct validity of the FBIS (Refer to Objective 1 in Section 5.2)	• Test-retest reliability was examined using scale and subscale mean scores of the FBIS at an interval of two weeks • Construct validity established by: exploring factor structure using the item mean scores of the FBIS, and comparing the contrasted groups (low patient care involvement group vs. high patient care involvement group)	FBIS questionnaire	• Pearson's product-moment correlation test • Exploratory factor analysis • Unpaired t-test (two-tailed) for comparison of contrasted groups
To test correlations between demographic variables and mean scores of the five scales within the questionnaire. (Refer to Objective 4 in Section 5.2)	Comparison between mean scores of the five measurement scales and: • Demographic variables in interval level, such as age and monthly household income • Demographic variables in ordinal level, such as education level and mental condition • Dichotomous demographic variables, i.e. gender of patient and family carer • Interrelationships between the five psychosocial measures	Questionnaire and demographic data	• Pearson's Product-moment correlation test • Spearman's rank correlation test • Point bi-serial test • Pearson's Product-moment correlation test

The Chi-square goodness of fit test was used to compare the observed frequency counts of subjects' socio-demographic characteristics with a known distribution within the underlying population (Portney & Walkins, 2000), in the New Territories region of Hong Kong where the outpatient clinic was located. This region comprised the largest population (i.e. about 20%) of patients with schizophrenia in Hong Kong. This comparison was one way to determine how well a sample represents its parent population (Polit & Hungler, 1999).

Correlation tests were used to examine relationships between demographic variables of the family carers and their respective scores of the five scales within the questionnaire. Inter-relationships between the five psychosocial measures and between demographic variables in interval level measurement and mean scores of the five scales were examined using Pearson's Product-moment correlation test. A scatter-plot for each pair of variables was generated to check for any violation of the assumptions of linearity and homoscedasticity (Gravetter & Wallnau, 2000). However, the graphs produced no cluster points, indicating no such violation. As indicated in Table 5.1, Spearman's rank correlation test and Point Bi-serial test were used to examine correlations between the mean scores of the five scales, and the ordinal level and dichotomous demographic variables, respectively.

Internal consistencies of the FBIS, FAD, SLOF, SSQ6, and FSSI were investigated by determining the Cronbach's alpha coefficients of overall scale and/or its domains, indicating homogeneity of construct of a scale. Pearson's product-moment correlation test was used to evaluate the test-retest reliability of the FBIS at an interval of two weeks. Construct validity of the FBIS was established by: comparing contrasted groups using an unpaired t-test (two-tailed), and performing an exploratory factor analysis. All statistical tests were two-tailed, with values of $p < 0.05$ considered significant.

According to Cuijpers (1999) and Martens and Addington (2001), the amount of time family carers spend performing caregiving tasks such as assisting with medication, personal hygiene and general physical care exerts a significant influence on families' perceived burden of caregiving. As such, it was hypothesised that, compared with the low patient care involvement group (i.e. 82 family carers spent an average of not more than 3 hours per day performing caregiver tasks), the high patient care involvement group (i.e. 80 carers with an average of not less than 4 hours per day performing caregiver tasks) would report significantly higher FBIS scores. To test this hypothesis and thus the construct validity of the Chinese version of the FBIS, a known group analysis was conducted.

5.4 TRANSLATION AND VALIDATION OF THE FAMILY BURDEN INTERVIEW SCHEDULE

Before the descriptive survey, the Family Burden Interview Schedule (FBIS) was translated into Chinese language (Mandarin) and tested for content validity and semantic equivalence with the original English version. Translation by one bilingual research assistant and back-translation by one translator of Chinese was undertaken independently. Their work focused on the conceptual or literal meaning of the items, as recommended by Bracken and Barona (1991). Key words about 'person' in some items, such as 'others', 'other members' and 'any member' were clarified and modified by the researcher to improve the translation. The resulting bilingual version of the FBIS was administered to 15 bilingual health professionals including registered psychiatric nurses, nurse specialists, psychiatrists, and medical social workers, and five family members who were caring for a patient with schizophrenia. The 20 panel members were asked to assess the appropriateness of the translation in addressing the original dimensions of the English version on a 4-point rating scale. They rated the appropriateness of each item as 1 = not appropriate, 2 = somewhat appropriate, 3 = appropriate, and 4 = very appropriate. Content validity of the CCFNI was estimated by calculation of a Content of Validity Index (CVI), which indicated the extent of agreement between the 20 experts. The Content Validity Index, representing the proportion of items that received a 3 or 4 rating of the 4-point rating scale used by the panel members, indicates acceptable level of validity when it is more than 0.85 (Waltz, Strickland & Lenz, 2005). In initial rating of the appropriateness of the translation by the 20 experts, only one item - 'Any other adverse effect on others' was deemed by four of them (20%) to be inappropriately translated and was amended. According to the expert panel review, the CVI of the overall Chinese version of the FBIS was 95% and of the items ranged from 90% - 100% (except the amended item), indicating similarity in content and dimensions with the original version, and thus it was considered to demonstrate an appropriate content validity (Portney & Watkins, 2000).

After testing the content validity, a convenience sample of 30 first-degree family members who were caring for a relative with schizophrenia or another psychotic disorder were asked to complete both versions of the FBIS. All of them had completed secondary school or university level of education and had adequate proficiency in English comprehension. They were selected conveniently from the same outpatient clinic for the pilot study (however, these families would be excluded

from the latter parts of the pilot study). One-half of respondents were given the Chinese version first and then the English version. The other half were administered the two versions in the reverse order, using a cross-over design with an interval of two weeks (Gravetter & Wallnau, 2000).

The semantic equivalence of the items between the Chinese and English versions of the FBIS was evaluated, using weighted kappa (Portney & Watkins, 2000). The item equivalence between the domains and total scores of the two versions of the FBIS was assessed using an intra-class correlation coefficient (ICC). There were 19 items with a kappa of greater than 0.8 and the remaining 6 items were between 0.54 and 0.68, representing a satisfactory level of agreement (Portney & Watkins, 2000). The ICCs between the two versions were 0.87 ($p < 0.03$) for total scores and from 0.80 to 0.89 ($p < 0.05$) for the six domains.

5.5 RESULTS OF THE SURVEY AND RELIABILITY AND VALIDITY OF FIVE INSTRUMENTS

The findings of the descriptive survey of the Chinese families caring for a relative with schizophrenia in one target outpatient clinic in Hong Kong, including the sample characteristics, test-retest reliability and construct validity of the FBIS, reliabilities of five research instruments, and inter-relationships between the instruments, are described as follows:

5.5.1 Sample characteristics

A total of 185 patients with schizophrenia and their families participated in this survey study out of 250 selected subjects and therefore the response rate was 74.0%. Thirty patients or families refused to participate in the study, 25 of them could not be contacted during the data collection period, and another 10 failed to complete the questionnaire. The socio-demographic characteristics (family carers' age, gender, education level, and monthly household income; and patients' age, gender, duration of illness, and mental condition in last three months) of the non-respondents were compared with the participants using Chi-square or t test (interval data); and there were no significant differences on these characteristics between the two groups ($p > 0.1$).

Among the family carers, there were more males (n= 102; 55.1%) than females (n= 83). Almost half of the sample (48.7%) was aged between 20 and 39 years, and the

mean age of the sample was 45.2 years (SD = 5.8). Over half of the sample received education up to secondary school level (53.0%), and almost three quarters (74.06%) had a monthly income of between Hong Kong dollars 5,000 – 15,000 (i.e. US$ 640 – 1,925). This monthly income was similar to the median monthly household income (HK dollars 8,000 – 12,000) of the Hong Kong population in 2002 (Census and Statistics Department, 2003). More than two-thirds of them (68.7%) were blood-related family members including children, parents and siblings of patients. The major socio-demographic characteristics of the family members are summarised in Table 5.2.

Table 5.2 Socio-demographic characteristics of families (N = 185) in pilot study

Characteristics	Frequency (%)	Mean (SD)
Gender		
Male	102 (55.1)	
Female	83 (44.9)	
Age & age range		45.2 (5.8)
20-29	35 (18.9)	
30-39	55 (29.7)	
40-49	73 (39.5)	
50 or above	22 (11.9)	
Education level		
Primary school or below	71 (38.4)	
Secondary school	98 (53.0)	
Tertiary [+]	16 (8.6)	
Relationship with patient		
Child	54 (29.2)	
Parent	48 (26.0)	
Spouse	37 (20.0)	
Sibling	25 (13.5)	
Others (e.g. grandparent)	21 (11.3)	
Monthly household income (HK$)#		12,500 (1,560) *
5,000 – 10,000	72 (38.9)	
10,001 – 15,000	65 (35.2)	
15,001 – 25,000	26 (14.0)	
25,001 – 35,000	22 (11.9)	

Note: * Non-significant differences between these subjects and the population of patients with schizophrenia in the same geographical region and the general population of Hong Kong as indicated from household survey data in 2001, using Chi-square test.
US$1 = HK$7.8; HK$12,500±1,560 = US$1,603±200.
[+] Tertiary level of education represents the diploma and degree qualifications from universities, technical schools and other professional institutes.

Table 5.3 Socio-demographic characteristics of patients (N = 185) in pilot study

Characteristics	Frequency (%)	Mean (SD)	Chi-square χ^2 *	df	P
Gender			1.87	1	0.19
Male	110 (59.5)				
Female	75 (40.5)				
Age and age range		38.1 (6.4)	4.87	3	0.28
20-29	40 (21.6)				
30-39	69 (37.3)				
40-49	66 (35.7)				
50 or above	10 (5.4)				
Education level			3.11	2	0.42
Primary or below	50 (27.0)				
Secondary	118 (63.8)				
Tertiary	17 (9.2)				
Mental condition in the past 3 months (possible range= 1–3)		2.1 (0.6)			
Improved (=1)	45 (24.3)				
Stable (=2)	113 (61.1)				
Worsened (=3)	27 (14.6)				
Number of family members living with patient		2.4 (0.6)	3.56	3	0.22
One	102 (55.1)				
Two	50 (27.0)				
Three – four	25 (13.6)				
More than four	8 (4.3)				
Present medication #			2.54	2	0.28
Low dosage	48 (26.0)				
Medium dosage	109 (58.9)				
High dosage	28 (15.1)				
Duration of illness		1.9 (0.5)	2.76	2	0.11
Within 1 year	70 (37.8)				
Between 1 – 2 years	80 (43.2)				
Between 2 – 3 years	19 (10.3)				
Between 3 – 4 years	16 (8.7)				

Note: * Comparison with the characteristics of patient population in the same geographical region reported by the Hospital Authority Hong Kong in 2001.

Medications taken by the patients are mainly conventional neuroleptics (85% of subjects) and some atypical ones (e.g. olanzapine; 15% of subjects); low dosage refers to that below the average dose recommended by the American Psychiatric Association Practice guidelines, measured in milligrams/day.

The major socio-demographic characteristics of the patients and the results of the Chi-square test are summarised in Table 5.3. Among the patients, there were also more males (59.5%) than females. More than half of them (58.9%) were aged between

20 and 39 years, with the mean age of 38.1 years (SD = 6.4). Almost two-thirds of them obtained secondary school (63. 8%) level of education. Most of the family carers commented that the mental condition of the patients within the last three months was stable or improved (85.4%). The majority of the patients (82.2%) had one or two family members living with them. Medications taken by the patients were mainly conventional neuroleptics (85.4%) such as chlorpromazine and in medium or low dosage (84.9%) as referred to the American Psychiatric Association Practice guidelines based on the results of different clinical studies (Bezchlibnyk-Butler & Jeffries, 1998). Most of the patients (81.08%) had less than two years of mental illness at data collection (M = 1.9 years, SD = 0.5). The ethnic group of the sample was mainly Chinese who were born in Hong Kong (91.90%) and from mainland China (5.40%). There were no significant differences between these patient characteristics and 2001 statistics for schizophrenia in the Annual Report of the Hospital Authority Hong Kong, using the Goodness of Fit Chi-Square test.

Table 5.4 indicates that Cronbach's alpha coefficients of the overall scales ranged from 0.84 to 0.88, indicating high internal consistency and reliability (Polit & Hungler, 1999). The reliability coefficients for the subscales or domains of the five psychosocial measures were high or satisfactory, ranging from 0.78 to 0.91 for the FBIS, 0.77 to 0.90 for the FAD, 0.90 and 0.91 for the SSQ6, 0.86 and 0.84 for the FSSI, and from 0.79 to 0.89 for the SLOF. The intra-class correlation coefficients (ICC) of the five scales with two ratings at one-week intervals between the researcher and the research assistant (the trained group facilitator) ranged from 0.77 to 0.89, whereas ICC > 0.75 indicated good inter-rater reliability (McGraw & Wong, 1996).

5.5.2 Reliability of the five psychosocial measures

The means and standard deviations of the five measurement tools: FBIS, FAD and its seven dimensions, SSQ6 (Number and Satisfaction scores), FSSI (number of services receiving and in need but not receiving), and SLOF and its three subscales are listed in Table 5.4. The 95% confidence intervals of the five scales, which represent the specific boundaries or limits with 95% chance that contain the population mean (Portney &Watkins, 2000), also indicated in the same table and encompassed a narrow range, and thus a precise estimation (Guyatt et al., 1995).

Table 5.4 Results of five psychosocial measurement tools

Instrument	Mean	SD	95% CI	Cronbach's Alpha coefficient	Intra-class correlation coefficient
FBIS (0 – 50)*	22.0	2.6	20.1 – 24.5	0.88	0.84
FAD (7 - 28)	16.9	1.2	15.1 – 17.5	0.84	0.80
Problem solving (1-4)	2.3	0.4	2.2 – 2.4	0.83	
Communication (1-4)	2.1	0.5	2.1 – 2.3	0.79	
Roles (1-4)	2.2	0.6	2.1 – 2.3	0.90	
Affective responses (1-4)	2.5	0.5	2.4 – 2.6	0.79	
Affective involvement (1-4)	2.4	0.5	2.3 – 2.5	0.77	
Behaviour control (1-4)	2.3	0.4	2.2 – 2.3	0.89	
General functioning (1-4)	2.4	0.7	2.3 – 2.5	0.88	
SSQ6 (0 – 6)					
Perceived availability (Number score)	2.9	0.6	2.9 – 3.1	0.91	0.88
Level of Satisfaction	3.0	0.7	2.9 – 3.1	0.90	0.89
Family Support Services Index					
Receiving (1-16)	4.9	0.9	4.8 – 5.0	0.84	0.85
Needing but not receiving (1-16)	3.9	0.9	3.8 – 4.0	0.86	0.81
SLOF (43 – 215)	150.1	8.2	132.9 – 175.7	0.84	0.77
Self maintenance (12-60)	62.8	6.1	58.6 – 66.2	0.79	
Social functioning (14-70)	41.7	5.2	36.8 – 44.1	0.89	
Community living skills (17-85)	45.6	5.9	41.2 – 47.9	0.85	

Note: * Possible range of scores of each scale or subscale indicated in parenthesis.

FBIS, Family Burden Interview schedule; FAD, Family Assessment Device; SSQ6, Six-item Social Support Questionnaire; SLOF, Specific Level of Functioning scale.

5.5.3 Test-retest reliability and construct validity of the FBIS

The test-retest reliability coefficients for the FBIS were 0.83 for overall scale and from 0.88 to 0.92 for the six domains: (a) family finance ($r = 0.89$); (b) family routine ($r = 0.90$); (c) leisure activities ($r = 0.92$); (d) interactions ($r = 0.92$); (e) physical health ($r = 0.91$); and (f) mental health ($r = 0.90$); and $p < 0.05$.

To test the hypothesis that the low patient care involvement group would report significantly higher FBIS scores than the high patient care involvement group (Cuijpers, 1999; Martens & Addington, 2001), a known group analysis was conducted. A significant difference was found in the overall FBIS scores between the high involvement group (M= 30.1, SD= 5.1), and low involvement group (M= 26.6, SD= 6.3; t (160)= 2.84, p= 0.01). There were also significant differences in the mean scores of the six domains between the two groups: (a) family finance [t (160)= 2.78, p= 0.01]; (b) family routine [t (160)= 2.91, p= 0.01]; (c) leisure activities [t (160)= 2.81, p= 0.01]; interactions [t (160)= 4.27, p= -0.001]; (e) physical health [t (160)= 2.55, p= 0.01]; and mental health [t (160)= 4.51, p= 0.001].

The 25 items in the Chinese version of the FBIS were subjected to principal components analysis. Prior to performing the analysis the suitability of the data for factor analysis was assessed. Inspection of the correlation matrix revealed the presence of all item-total coefficients > 0.30 (range 0.32 to 0.68). The Kaiser-Meyer-Oklin value was 0.80, exceeding the recommended value of 0.60 and the Barlett's Test of Sphericity reached statistical significance, supporting the factorability of the correlation matrix (Stevens, 2002). According to the inter-item correlation matrix, none of the 25 items was considered redundant.

Principal components analysis revealed the presence of five components with eigen-values exceeding one, explaining 65.8% of the variance in the scale (refer to Table 5.5). Using Catell's scree test, it was decided to retain all five components for further investigation.

Table 5.5 Result of principal component analysis of the FBIS (N = 185)

Factor	Eigenvalue	Percentage of variance explained	Cumulative percentage
Family finance	5.3	24.2	24.2
Family activities	3.2	17.3	41.6
Family interactions	2.2	10.7	52.2
Physical health	2.1	8.5	60.8
Mental health	1.3	5.0	65.8

Note: FBIS, Family Burden Interview Schedule.

Varimax rotation was performed and the rotated solution revealed the presence of a simple structure, with each component showing a number of strong loadings and all variables loading substantially on only one component. The results of the Varimax

rotation are presented in Table 5.6 and only slight changes in the percentage of the variance explained by each factor were found. The variance explained by the five factors was 64.7%. The results suggest that the two domains - 'family routine' and 'family leisure' should be combined into one factor called 'family activities'. One item - 'Other family members missing school, meals, etc.', was loaded onto the factor 'physical health' instead of 'family activities'.

Table 5.6 Varimax rotation of the five-factor solution for the FBIS items

Factor and items	Factor loading	Percentage of variance explained
Factor 1. Family finance		23.3
1. Loss of patient's income	.78	
2. Loss of income of other family members	.79	
3. Expenses of patient's illness	.81	
4. Expenses due to other necessary changes in arrangements	.61	
5. Loans taken	.77	
6. Any other planned activity needing finance, postponed	.88	
Factor 2. Family activities		20.3
1. Patient not attending work, school, etc.	.52	
2. Patient unable to help in household duties	.73	
3. Disruption of activities due to patient's illness and care	.81	
4. Disruption of activities due to patient's irrational demands	.70	
5. Stopping of normal recreational activities	.89	
6. Absorption of another member's holiday and leisure time	.85	
7. Lack of participation by patient in leisure activity	.72	
8. Planned leisure activity abandoned	.84	
Factor 3. Family interactions		8.5
1. Ill effect on general family atmosphere	.52	
2. Other members arguing over the patient	.61	
3. Reduction or cessation of interaction with friends & neighbours	.60	
4. Family becoming secluded or withdrawn	.69	
5. Any other effect on family or neighbourhood relationships	.81	
Factor 4. Physical health		7.2
1. Physical illness in any family member	.83	
2. Any other adverse effect on others	.50	
3. Other family members missing school, meals, etc.	.68	
Factor 5. Mental health		5.3
1. Any member seeking professional help for psychological illness	.73	
2. Any member becoming depressed, weepy, irritable	.81	
3. How you have suffered owing to patient's illness	.60	

5.5.4 Relationships between demographic characteristics of subjects and their scores on psychosocial measures

As shown in Table 5.7, there were significant and negative correlations between the FAD, SSQ6 – Number (of supporting person) score, and SSQ6 -

Satisfaction score. The FAD was also significantly and negatively correlated with the two FSSI subscales - 'Receiving' and 'In Need but Not Receiving'; and positively correlated with the SLOF and FBIS. The FBIS was significantly and positively or negatively correlated with all other scales, except Family Support Services subscale- 'In Need but Not Receiving'. This indicated that family caregivers with higher level of burden of care showed poorer family functioning, less amount and satisfaction of social support, receiving fewer family support services, and caring for a patient with lower level of daily functioning. This FSSI - 'In Need but Not Receiving' subscale showed significant but negative relationship with the SSQ6 - Number score.

For the correlations between the family characteristics and five measures, the results are also indicated in Table 5.7. Relationship with patient was significantly correlated with the FBIS and FAD, using point bi-serial correlation test. The FSSI - 'Receiving' subscale was positively correlated with education level, whereas the FBIS was negatively correlated with monthly household income.

Results of these correlations between patient characteristics and psychosocial measures are summarised in Table 5.8. The number of family members living with the patient was significantly and positively correlated with the FAD but negatively correlated with the FBIS. This indicated that a higher number of family members at home might reduce the family burden of care, but not necessarily improve, and possibly even worsen, the overall family functioning. Duration of patient illness was positively correlated with the FBIS and average number of family support services receiving, and negatively correlated with the SLOF. Mental condition of patient (1– Improved to 3– worsened) during the last three months was positively correlated with the FBIS, FAD and present medication dosage (i.e. the more improved the mental condition of the patient, the better the family functioning, and the lower the family burden and medication dose); and conversely, it was negatively correlated with the SLOF (i.e. the more improved the mental condition of the patient, the higher the overall patient functioning). The relationship between the present dosage of medication and SLOF was significant but negative. Otherwise, there were no statistically significant correlations between the measures and other socio-demographic variables.

Table 5.7 Inter-correlations of family characteristics and five psychosocial measures

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1 Age	1.00	.12	.10	.13	.08	.32	.45	.34	.28	.39	.24	.34
2 Gender		1.00	.30	.40	.27	.45	.40	.41	.44	.38	.35	.31
3 Education level			1.00	.16	.81##	-.41	.38	.43	.48	.53#	.42	.45
4 Relationship with patient				1.00	.11	.61+	.64+	.38	.31	.31	.30	.40
5 Monthly income					1.00	-.68*	-.36	.21	.36	.41	.41	.35
6 FBIS						1.00	.66*	-.76*	-.67*	-.71*	-.43	-.64*
7 FAD							1.00	-.81**	-.72*	-.68*	-.62*	.68*
8 SSQ6– Number score								1.00	.89**	.48	.39	-.44
9 SSQ6– Satisfaction score									1.00	.41	-.53*	-.40
10 Family Services- receiving										1.00	-.38	-.34
11 Family Services- in need											1.00	.43
12 SLOF												1.00

Note: #: $p < 0.05$ and ##: $p < 0.01$, Spearman's rank correlation test.
+: $p < 0.05$, point bi-serial correlation test.
*: $p < 0.05$ and **: $p < 0.01$, Pearson's product-moment correlation test.
FBIS, Family Burden Interview schedule; FAD, Family Assessment Device; SSQ6, Six-item Social Support Questionnaire; SLOF, Specific Level of Functioning scale.

Table 5.8 Inter-correlations of patient characteristics and five psychosocial measures

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1 Age	1.00	.10	.05	.23	.38	.42	.25	.38	.18	.21	.14	.23	.12	.46
2 Gender		1.00	.20	.30	.33	.35	.30	.31	.14	.22	.11	.10	.03	.21
3 Education level			1.00	.26	.41	.31	.28	.33	.38	.37	.22	.13	.24	.45
4 Family members living with patient				1.00	.21	-.34	.39	-.58*	.61*	.31	.40	.29	.12	.30
5 Duration of illness					1.00	.35	-.36	.61*	.46	-.41	-.31	.55*	.44	-.53*
6 Mental condition						1.00	.61#	.55#	.71#	-.38	-.34	-.45	.33	-.81##
7 Present medication							1.00	.38	.41	.25	.26	-.31	.42	-.58#
8 FBIS								1.00	.66*	-.76*	-.67*	-.71*	-.43	-.64*
9 FAD	1.00	-.81**	-.72*	-.68*	-.62*	.68*								
10 SSQ6– Number score		1.00	.89**	.48	.39	-.44								
11 SSQ6– Satisfaction score			1.00	.41	-.53*	-.40								
12 Family Services-receiving				1.00	-.38	-.34								
13 Family Services- in need					1.00	.43								
14 SLOF						1.00								

Note: #: $p < 0.05$ and ##: $p < 0.01$, Spearman's rank correlation test.
*: $p < 0.05$ and **: $p < 0.01$, Pearson's product-moment correlation test.
FBIS, Family Burden Interview schedule; FAD, Family Assessment Device; SSQ6, Six-item Social Support Questionnaire; SLOF, Specific Level of Functioning scale.

5.6 SUMMARY AND CONCLUSION

This first phase of the pilot study served the purposes of establishing the reliability and validity of the instruments (FBIS, FAD, SSQ6, SLOF, and FSSI), which were used in the main study, and of obtaining an overview of the psychosocial conditions of 185 Chinese families caring for a relative with schizophrenia in a major geographical region of Hong Kong. There were non-significant differences between the families and their patients in this pilot study and the population of patients with schizophrenia in the same geographical region and the general population of Hong Kong, as indicated from household survey data in 2001 and the Annual Report of the Hospital Authority Hong Kong in 2002. As indicated from the mean scores of the five scales, the families indicated a moderate level of burden, functioning, social support, and patient functioning. The families were receiving on average four to five mental health services in the list (FSSI); however, they reported that they were deprived of about four items of services in need.

The Cronbach's alpha coefficients of the five instruments and their subscales were between 0.77 to 0.91, indicating satisfactory to high levels of internal reliability. The five instruments also indicated good inter-rater reliabilities, whereas their intra-class correlations with two ratings at one-week intervals between the researcher and the research assistant ranged from 0.77 to 0.89.

The primary outcome measure, Family Burden Interview Schedule (FBIS), was translated into Chinese language (Mandarin) and back-translated to English with satisfactory reliability and validity testing results. It was found that the Chinese version of the FBIS addressed adequately the original concepts and dimensions and achieved 95% on the Content Validity Index and only one item - 'Any other adverse effect on others' was amended in translation. The Chinese version demonstrated high levels of equivalence with the original English version (ICC of 0.87 for the overall scale and 0.80 - 0.89 for six domains). It also demonstrated adequate test-retest response stability ($r = 0.83$ and 0.88 - 0.92 for the scale and domains, respectively) at a two-week interval. Contrast groups analysis was conducted and significant differences were found in the overall FBIS score and its six subscales between the high patient care involvement group (80 family carers, with an average of not less than 4 hours per day performing caregiving tasks) and the low patient care involvement group (82 family carers, with an average of not more than 3 hours per day performing caregiving tasks). The principal components analysis with varimax rotation revealed the presence of five

factors (family finance, family activities, family interactions, physical health, and mental health), which together explained 64.71% of the total variance of family burden. It also demonstrated high factor loadings, item-to-scale and between subscales inter-correlations, indicating good construct validity of the burden measure. Statistically significant correlations were found between the outcome measures and some selected socio-demographic characteristics of the sample and these relationships would be checked again when multivariate statistical analysis of treatment outcomes was performed in the main study.

The findings of the psychometric properties of the Chinese version of the FBIS established its potential as a research instrument in measuring caregiver burden for Chinese patients with schizophrenia. The satisfactory internal consistencies and inter-rater reliabilities of the FBIS and other four instruments found in this pilot testing ensured that they are psychometrically sound when used in main study.

CHAPTER 6 METHODS OF THE MAIN STUDY

6.1 INTRODUCTION

Following the presentation of the aims and objectives and testing the hypotheses of the main study, this chapter presents the design and method used to examine the effectiveness of a mutual support group programme on a number of short-term and substantive family and patient outcomes to families caring for a relative with schizophrenia in Hong Kong. First, the aims and objectives of the study are described and the study hypotheses used to confirm the effectiveness of the mutual support group to the Chinese families of patients with schizophrenia are listed in Section 6.2. Sections 6.3 and 6.4 present the research design and the sampling method and research venues used in this 18-month clinical trial, respectively. The procedures of recruitment and randomisation of the participants in the clinical trial and a flow diagram to summarise the trial design are presented in Section 6.5. The treatment conditions including description of the treatment group (mutual support) and control group (usual outpatient care only), and training of the group facilitator are described briefly in Section 6.6. The instruments used for outcome evaluation of the mutual support group used in this study are described briefly in Section 6.7 and a detailed description of these instruments can be found in Section 5.3.5 (Chapter 5). The use of semi-structured interviews of the support group participants and audio taped group sessions for process evaluation of the support group are also presented in Section 6.8. Data collection and analysis procedures are described in Sections 6.9 and 6.10, respectively, in which the strategies for quantitative data analyses of the trial and the content analysis of the interview and group session data are explained. Finally, issues of reliability and validity for the RCT and qualitative methods (Sections 6.11 and 6.12) and ethical considerations (Section 6.13) to be addressed in this PhD study are discussed.

6.2 AIMS, OBJECTIVES AND HYPOTHESES

The purpose of this clinical trial was to assess the effectiveness of a mutual support group programme designed to help families of patients with schizophrenia in Hong Kong cope better with their caregiving role and the consequences of this role for their family life. Families who participated in the mutual support group intervention were compared with those who received usual psychiatric outpatient services on a variety of family and patient outcome measures. The primary outcome of the study was the family carers' perceived burden of care,

which measures the distress level of families caring for a relative with schizophrenia in terms of physical, psychological, social, and financial aspects (Pai & Kapur, 1982).

6.2.1 Objectives of the study

The main objectives of this study were to:

1. Estimate and compare the immediate impact and substantive effect of a mutual support group plus usual psychiatric outpatient service (the intervention) with usual outpatient service alone (the comparison) for a group of Chinese families caring for a relative with schizophrenia managed within two psychiatric outpatient clinics in Hong Kong on:

a) A primary outcome: family burden of care;

b) Secondary family outcomes: family functioning, perceived social support, family conflicts and utilisation of available family support services.

2. Estimate and compare the impact between the two interventions on the following patient outcomes: level of functioning, symptom severity and length of re-hospitalisation over the 12-months follow up period.

3. Identify the therapeutic mechanisms of the mutual support group model of family intervention for patients with schizophrenia.

6.2.2 Study hypotheses

To confirm the efficacy of the mutual support group used in this study for families caring for a relative with schizophrenia, the following null hypotheses were tested:

- H1: There will be no significant difference in perceived family burden of care between the families who participated in the mutual support group (and usual outpatient service) and the control group who received only the routine outpatient service, over a 12-month follow-up period.
- H2: There will be no significant differences in family psychosocial outcomes (i.e. family functioning and perceived social support) between the families who participated in the mutual support group and the controls who received only usual psychiatric outpatient service, over the follow-up period.
- H3: There will be no significance differences in the patients' psychosocial functioning, symptom severity and length of re-hospitalisation between the treatment (mutual support) and control groups, over the follow-up period.

Other variables, including the amount of family conflicts, number of support persons and demand in family services were examined and compared between the two groups.

6.3 RESEARCH DESIGN

The study was designed to delineate the causal relationships between participation in a mutual support group intervention and improvement of family psychosocial conditions, and thus enable the hypotheses in Section 6.2.2 to be tested. A randomised controlled trial (RCT), with a controlled group and repeated measures design, was used to assess and compare the immediate (one week after intervention), six-month and 12-month effects of the mutual support group programme and the conventional patient-focused service provided by the psychiatric outpatient clinics, to Chinese family carers of a relative with schizophrenia in Hong Kong. The RCT is a well-established approach to scientific investigation that consists of specific treatment and a series of observations on the subjects' conditions under environment or conditions controlled by the researcher (Matthews, 2000). The families who participated in the mutual support group were the treatment group and those who received the usual psychiatric outpatient services only served as the controls. The study was conducted on families of patients with schizophrenia in two psychiatric outpatient clinics (OPDs) in the New Territories, a geographical region with the largest patient population in Hong Kong.

Within this design, the researcher manipulates the levels of the independent variable (i.e. mutual support group intervention used in this study) and incorporates elements of control (e.g. ensuring the sample is not participating in another individual or multiple-family therapy), so providing a strong foundation for making decisions about the relative efficacy of different treatments or interventions (Brink & Wood, 1998). Besides the manipulation or control of variables, other characteristics of a RCT should be present to ensure the validity of outcomes (Bailer & Mosteller, 1992; Portney & Watkins, 2000). By operating to these characteristics or standards, a RCT such as in this study can minimise the possibility that study outcomes are caused by factors other than the intervention used. These important characteristics include:

- Random selection and distribution of subjects into experimental and control groups to ensure no systematic differences that influence the outcomes between the two groups. In this study, a computer was used to generate a random list of numbers, which determined the study subjects' selection according to the patient list from the outpatient clinics, and to generate random block numbers, which determined their allocation into the two groups;
- Presence of controls, which are treated identically as experimental subjects except the specific treatment to be tested. In this study, the experimental group received the mutual

support group intervention and usual psychiatric outpatient service and the control group received standard outpatient service only;

- Blinding of treatment conditions to subjects, clinicians and researcher, or to one side if not feasible to be double-blinded, to avoid bias or preconceived views of researcher, clinicians and subjects influencing the treatment effect and assessment of outcomes. The staff in the clinics were blind to the families recruited in this study and the researcher was blind to the allocation of the subjects to the groups;
- Specific protocol of treatment, e.g. positioning of subjects, timing of all treatments and measurements and treatment procedures, to minimise variability of subjects' experiences of the intervention within their group. A comprehensive mutual support group programme (described in Chapter 4) was pilot tested before being used in this trial. In addition, a group facilitator (a registered psychiatric nurse) was trained with a three-day workshop by the researcher and family therapist to implement the group programme; and
- Analysis of data on an intention-to-treat basis to maintain the advantages of random allocation, which may be lost if subjects are excluded from the final data analysis when they withdraw or fail to comply. This principle of data analysis was used in this trial.

The use of clinical trials is considered as the gold standard for judging the benefits of treatments, mainly because it is conceptually easier to attribute any observed effect to the treatments being compared (Medical Research Council, 1998; Altman et al., 2001). However, Altman et al. (2001) emphasise that clinical trials with inadequate methodologic approaches are associated with exaggerated or biased treatment effects; and many reviews have documented deficiencies in reports of clinical trials and thus reported results may be misleading.

Although the RCT is considered the most reliable method of assessing the efficacy of health care interventions, more than half of the RCTs published in the medical and health care journals do not report clearly one or more aspects of the study, such as the design, data collection procedure, data analysis strategies, and results, and so provide inadequate information to assure confidence in the validity of the trial (Schulz et al., 1995). Matthews (2000) also argues that it may be difficult to maintain a well-controlled experimental environment in frequently changing clinical practice settings, and to apply standards of an RCT, such as blinding of subjects or clinicians to interventions and subjects' refusal to receive specific treatment.

In response to these criticisms, the Consolidated Standards of Reporting Trials (CONSORT) statement (first published in The Journal of the American Medical Association in 1996) has been supported to be a widely adopted guideline to facilitate proper design and execution of clinical trials (Begg et al., 1996). The revised version in 1999, consisting of a checklist of 22 items for reporting a RCT and a flow diagram showing the flow of participants through each stage of a trial (Altman et al., 2001), was used as the methodological and documentation standard for this study. This statement provides key and helpful information necessary to evaluate the internal and external validity of the report and thus the readers can judge whether the treatment effects and findings are likely to be valid.

A repeated-measure, pre-test and post-test study design was also used. One week before intervention, the subjects of the experimental and control groups were asked to complete the pre-test questionnaires. Three post-test measures, at one week, six months and 12 months after the intervention, provided information for comparing the immediate and long-term effects between the mutual support (experimental) and standard care (control) group. Nevertheless, as pointed out by Pharoah et al. (2001), the researcher was also interested in understanding the specific ingredients of the mutual support group intervention for patients with schizophrenia, which might lead to better family and patient outcomes. Family interventions have been found to exert significant long-term effects on patients and their families by some studies but not by others. It was therefore considered important to examine these long-term effects of the mutual support group intervention used in this study on the families of patients with schizophrenia, and to identify the components of the intervention, which contributed to the significant positive family and patient outcomes measured in the study.

In addition, the study also aimed to identify the therapeutic mechanisms of the mutual support group as an effective model of family intervention for patients with schizophrenia (i.e. to achieve the Study Objective 3 stated in Section 6.2.1). Face-to-face semi-structured interviews of the group participants and examination of the content of the audio-taped group sessions were conducted to explore the perceived benefits and limitations of the mutual support group, the group development and integrity, and the individual and group levels of changes among the participants throughout the 12 sessions.

6.4 SAMPLE AND RESEARCH SITES

To ensure that the measured effects are the result of the mutual support group intervention being tested, the competing interventions must be applied to a representative patient population and sample (Wolff, 2000). The target population of this study consisted of Chinese family members who lived with and were the primary caregivers of a relative with schizophrenia. These patients attended for follow-up at the two psychiatric outpatient clinics in the New Territories, the largest geographical region and patient population in Hong Kong. Since 1991, the Hospital Authority, Hong Kong, has run all the psychiatric outpatient clinics in Hong Kong. According to the Statistical Report of the Hospital Authority, Hong Kong (2003), there were in total about 1,500 outpatients diagnosed with schizophrenia and other psychotic disorders according to the criteria of the DSM-IV (American Psychiatric Association, 1994), and receiving follow-up treatments at the two outpatient clinics under study. However, 985 of them were primarily diagnosed with schizophrenia and without co-morbidity of another mental illness; and this patient population represented approximately 10% of the total outpatients with schizophrenia in Hong Kong in 2003. These patients consisted mainly of Chinese people born in Hong Kong (n= 853, 86.6%) or from mainland China (n= 117, 11.9%).

Preliminary checking of the major demographic characteristics of this patient population with those of the total population of outpatients with schizophrenia in Hong Kong (i.e. data from the Hospital Authority, Hong Kong in 2003), specifically gender, age, education level, living arrangement, health care service utilisation, and duration of illness, found no significant differences between the population for this study and the total population of outpatients with schizophrenia and other psychotic disorders in Hong Kong (i.e. non-significant differences using Goodness of Fit Chi-Square or unpaired t test and $p > 0.05$). Similar to the previous studies in Western and Asian countries (Chan & Yu, 2004), a higher percentage of the population under study were male patients (65.0%) and aged between 20 – 35 years (68.0%); and a higher percentage of primary caregivers were female (60.0%).

The study was conducted over an 18-month period between August 2003 and February 2005. About 200 families (20.3% of 985 patients with schizophrenia) in the two clinics met the sample criteria listed in Section 6.4.2 during the subject

recruitment. They were selected as eligible subjects and were approached by a research assistant for consent to participate in the trial.

6.4.1 Sample for the clinical trial

Statistical advice was obtained from a statistician with substantial experience of clinical trials and epidemiological research studies. The required sample size of 76 families for this trial (38 subjects in each arm of the study) was based on the following information and assumptions:

a. The primary outcome of interest was a reduction of families' burden of care as assessed by the Chinese version of Family Burden Interview Schedule (FBIS). The unit of analysis was those family members living with and caring for a patient with schizophrenia during the study period.
b. A fairly large effect size (eta squared statistics of 0.68) was anticipated when the FBIS post-test mean score for the mutual support group intervention was compared with the usual psychiatric outpatient care in the pilot study, using analysis of covariance (ANCOVA). Moreover, two previous clinical trials by Xiong et al. (1994) and Zhang et al. (1993) found a significant decrease in the level of overall family burden for Chinese families in post-tests of a family psycho-education group intervention with education and problem-solving training, compared with standard care of families. Large effect sizes of 0.68 and 0.75, respectively, were also demonstrated immediately after the intervention.
c. The most conservative method of analysis would be a comparison of differences in mean scores between two groups at pre-test, post-test and follow-up measurements using a repeated measures univariate or multivariate analysis of variance.
d. The level of significance for detecting a significant effect on the FBIS was set at 5% and the selected level of power for test of difference of means was 0.80.
e. According to Cohen (1992) and Stevens (2002), a medium to large effect size could be expected for studies in behavioural sciences when the intervention is highly structured and an effect likely to be visible to the naked eye of an observer. Thus, a sample of about 30 subjects per group would be required in a two-group study with an estimated effect size of 0.70, achieving a power of 0.80.
f. The anticipated attrition rate of 25% was calculated from the reports of 10 RCT studies on group intervention for families of patients with schizophrenia from 1978

to 1997, reviewed by Barbato and D'Avanzo (2000). Hence, the required sample size of this trial was 38 subjects per group.

Random assignment of subjects to the experimental or control group was used in this study to ensure that any systematic or uncontrolled differences within the sample would be randomly distributed between the two interventions (mutual support and usual care). However, this random assignment did not guarantee that both the experimental and control groups were equivalent, particularly with a small sample, as in this study (Wolff, 2000). Stratified sampling (refer to Section 6.5.2) was employed therefore to ensure an equal number of subjects from each of the two clinics under study; and the socio-demographic characteristics and psychosocial functioning of the subjects (families) within the two groups were compared to assess the homogeneity of the two groups at baseline measurement.

6.4.2 Subject selection criteria

In principle, inclusion and exclusion criteria of subjects for a clinical research study clearly define and shape the characteristics of the study sample, by which a true or eligible subject can be selected from the target population. Moreover, an unclear boundary of study population, sample and research site can have direct impact on the generalisability of the findings from a clinical trial to the real world, the complex social environment and services (Matthews, 2000). In view of this, sampling criteria are clearly described as below.

Inclusion criteria of subjects for this trial were family carers who:

- Lived with and cared for one relative with a primary diagnosis of schizophrenia according to the criteria of the DSM-IV (American Psychiatric Association, 1994);
- Cared for the relative with no co-morbidity of another mental illness during recruitment and whose duration of the illness was not more than five years;
- Were aged 18 years or above and could understand and read Chinese language (Mandarin or Cantonese); and
- Were free from any psychiatric disorder or chronic physical illness themselves.

If more than one family member was eligible to participate in the study, each family was asked to identify the primary carer who had most contact with and took care of the patient most frequently to be the participant of the study. The research assistant

approached that family carer and written consent was sought to participate in the study, with full explanation of the purpose and procedure of the study. This strategy for selecting the participants in the study worked very well.

Families were excluded if they took care of more than one family member with mental illness or those who had taken care of the patient for less than three months. The minimum time of three months' caregiving experience was chosen as one subject selection criterion because it was essential to ensure that the sample had adopted the caregiving role and that they and their families encountered and recognised different psychosocial problems in caring for their relative with schizophrenia. Those families who had already participated or were participating in any individual family or group therapies for caregivers of patients with schizophrenia were also excluded from the study because this might result in a confounding or uncontrolled effect on the families for testing the interventions used in this study.

6.5 RECRUITMENT AND RANDOMISATION PROCEDURES

The methods and procedure of sample recruitment and randomisation for this trial are described in this section, with reference to the criteria and standards for RCTs in the revised CONSORT statement (Altman et al., 2001). The details are:

6.5.1 Recruitment

All patients with a medical diagnosis of schizophrenia at the two target outpatient clinics in Hong Kong were listed from the computerised record of outpatients with the assistance of the clinical staff. Key information held on the patients in the records was checked and patients were short-listed by the researcher to obtain those who: (a) were diagnosed with schizophrenia but not any co-morbidity of another mental disorder; (b) had an onset of the illness for not more than five years; and (c) were living with at least one of their family members. One research assistant in the clinic approached these eligible patients in person during their follow-up appointment. A study information sheet (see Appendix 8) was used to explain the purpose and procedures of the study and its potential benefits and risks for participants. Eligibility to be the subjects in this study was also checked according to the study criteria in Section 6.4.2. When obtaining their written consent, the potential subjects (patients) were asked for permission to approach their family for participation via face-

to-face or telephone contact. Patients took the information sheet home and used this as a basis for discussion of participation in the trial with their family before being contacted by the research assistant.

Each family was asked by the research assistant to identify one primary carer to be the participant in the study who was in contact with and took care of the patient most frequently. Eligible participants (family carers) received written information about the study and this information was also fully explained to them by the research assistant. Adequate time was allowed for them to ask questions about their participation in the study and the research assistant responded to their questions. They were then offered entry to the trial and invited to the outpatient clinic at their convenience to sign a consent form (see Appendix 8) and, at the same time, carry out the randomisation procedure.

6.5.2 Method of randomisation

In order to ensure that a similar number of subjects were selected from each clinic under study, the subjects were stratified into two sets of people, clinic 1 and 2, and thus 38 subjects (i.e. 19 subjects for each study group) were chosen from each clinic. After obtaining family carers' written consent, thirty-eight family carers were randomly selected from each clinic from a list of 62 and 68 potential subjects, which were arranged in alphabetical order of their names, in clinic 1 and 2 respectively, using a computer generated random number table.

These family carers were then allocated to either the mutual support group or the control group using a restricted block randomisation procedure. Randomisation sequences of four numbers were prepared from a table of random numbers, each block comprising two 'A group' and two 'B group' allocations. This restricted randomisation resolved the possible problem of unbalanced group sizes using simple randomisation, and thus reduced the risk of loss of power (Matthews, 2000). The procedure meant that after every fourth subject the two groups were of the same size. Randomised generated treatment allocation sequence of each stratum was then prepared and the letters representing the group allocation (A = mutual support group; B = control group) were placed by the researcher inside individual sealed opaque envelopes. The two sets of envelopes were put in to separate boxes labelled with the name of the clinic and were kept by the research assistant. The research assistant met the 76 family carers who had

been randomly selected from the name list individually at an interview room in the clinics and opened the envelope with a pre-determined and randomised treatment sequence. Therefore, the research assistant was blinded to the treatment allocation (Brink & Wood, 1998) and thus not aware to which group the family was allocated until the envelope was opened.

The research assistant opened the envelope, told the family carers which group they were allocated to and explained what participation in the experimental or control group involved. The final list of the subjects in each group was established and kept by the research assistant. The researcher and clinic staff were blinded to the allocation. Nevertheless, the clinic staff were well-informed about the purpose and procedures of the trial and they were asked for assistance in the process of intervention such as checking the patients' records and booking room and equipment for group meetings. The clinic staff and the researcher who undertook the outcome measurements also did not have access to the group list.

6.5.3 Flow diagram summarising the trial design

The key information of the RCT design is summarised in the following diagram (Figure 6.1) according to the suggestions from the revised CONSORT statement (Altman et al., 2001). As shown in the figure, families of outpatients with schizophrenia (n = 200) who met the study criteria were invited to participate in this trial by the research assistant (trained group facilitator) during their follow-up consultation in the two outpatient clinics under study. Of these, 130 families consented to participate and their names were listed in alphabetical order. Seventy-six were randomly selected from the list using a random number table and they were then randomly allocated to the experimental and control groups (i.e. 38 families in each group). The remaining 54 families were put on a waiting list for similar mutual support groups after the six-month period of intervention for this study, or other family therapies if they requested. The families in the experimental group underwent the mutual support group intervention as well as the usual psychiatric outpatient care for six months whilst the control group received the routine psychiatric outpatient care only. The researcher assessed the health condition of the family carers and their patients in the two study groups during recruitment (baseline) and at three times (one week, six months and 12 months) after the interventions.

The researcher also monitored the subjects' attrition during 12 months following the interventions and analysed the attrition bias to the outcomes of both the experimental and

control groups. Since data analysis for this trial had been designed on intention-to-treat basis, all subjects' data were used in the final analysis, with the exception of those who were withdrawn from the study before the pre-test, or who were found incompatible with the sample criteria before the interventions (Gibaldi & Sullivan, 1997; Montori & Guyatt, 2001). However, only a limited number of subjects failed to complete the interventions and the data of all subjects (n = 76) were used in the final analysis of data in this trial.

6.6 TREATMENTS

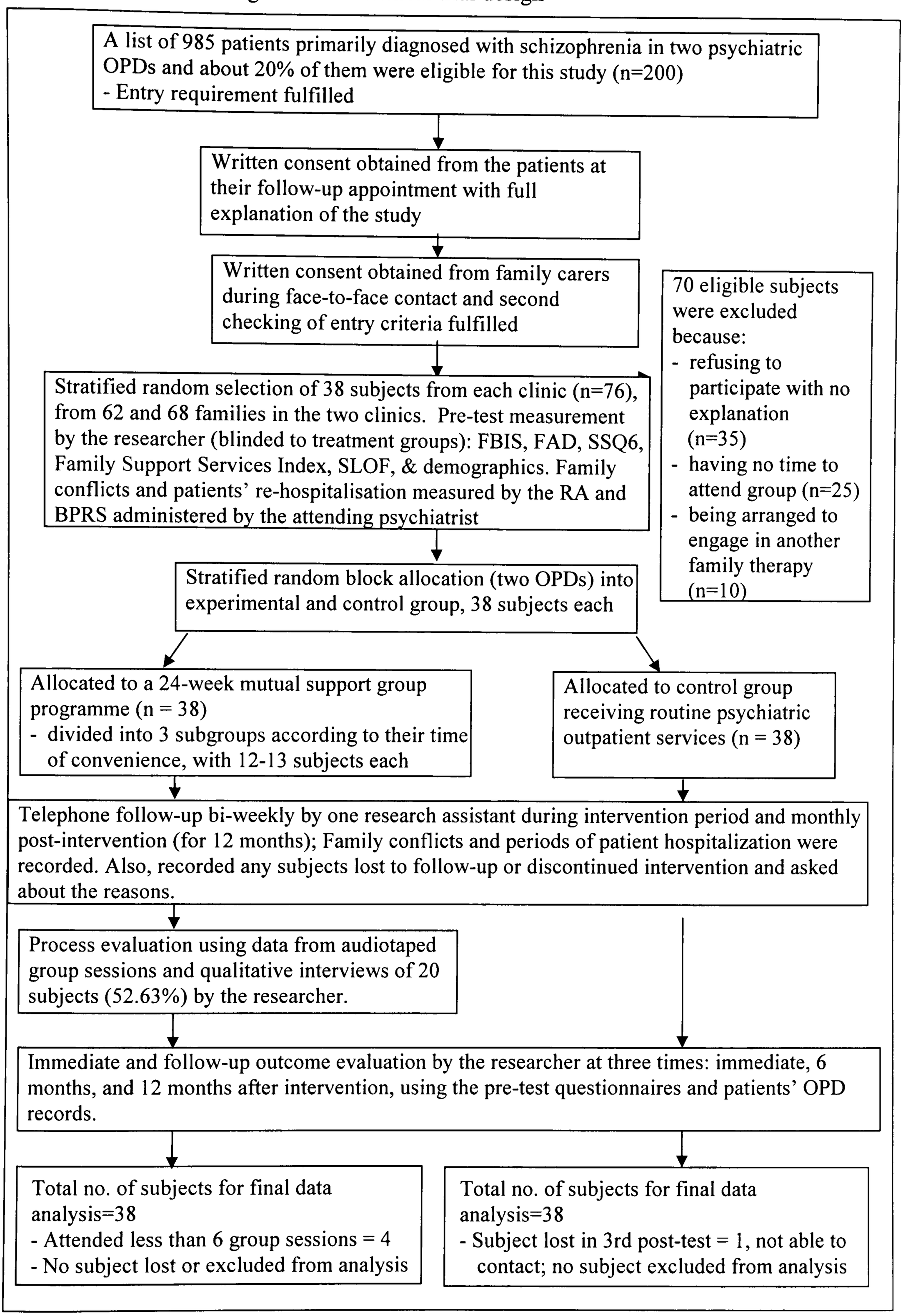
The treatments received by the experimental and control groups are presented briefly in this section. The detailed description of the mutual support group programme for the experimental group of this study was presented in Chapter 4.

6.6.1 Experimental (mutual support) group

Subjects (n = 38) randomised to the intervention group received a six-month mutual support group programme and at the same time, they also received the usual mental health care service provided to the patients and their families having follow-up in the psychiatric outpatient clinics. Subjects in this treatment group were randomly assigned to three sub-groups (i.e. 12-13 subjects in each subgroup), which was an appropriate group size for participants to become actively involved in group discussion and sharing (Yalom, 1995). However, subjects of the intervention group were asked not to inform the medical and nursing staff of the clinic about their participation in this study and not to engage in any other family therapies during the intervention period. Any questions and queries about the study and patient care were discussed in the group sessions or during the telephone follow-up with the group facilitator (trained research assistant for the study). The facilitator, if needed, could refer families to the clinic staff and to other appropriate family support services.

During the six-month intervention, bi-weekly telephone follow-up was conducted by the facilitator in order to encourage study participants to attend the group sessions and collect on-going data on family and patient conditions, including family conflicts and patient's re-hospitalisation and changes in medication. The follow-up also aimed to collect information about the services that families had received within each period. As part of the intervention, the facilitator answered questions from group participants and made referrals to supporting services, if needed.

Figure 6.1 Flow diagram of the clinical trial design



6.6.2 Control group

Subjects (n=38) randomised to the control group received only usual psychiatric outpatient services provided by the outpatient clinics, mainly medical consultation and advice from a psychiatrist, home visits by community psychiatric nurses, social welfare and financial services provided by a medical social worker, and if necessary, individual family counselling by a clinical psychologist (refer to p.18).

During each patient's psychiatric follow-up appointment in the clinic, the family carers or their patients were asked by the research assistant (group facilitator) about data on families and patients' health status, and services received within the specific period, in the same way as the experimental group.

6.6.3 Subsequent management of intervention and control groups

After the six-month intervention period, subsequent management of the study subjects was identical for the experimental and control groups including:

- Receiving the usual psychiatric outpatient service and other mental health services.
- Telephone contact every month by the researcher for one year, to continue to follow-up the families and patients' conditions and, by the group facilitator, to obtain data on family conflicts, periods of patient re-hospitalisation, changes in medication, and any mental health care services received by the family. However, any questions related to patient condition and progress, family support service and other mental health services, were referred immediately to the clinic staff.
- However, all participants were free to participate in any family therapy or intervention provided by the clinics after the six-month intervention.

On completion of the study, the control group subjects were invited to participate in a similar support group if they preferred, particularly when the results of the support group intervention had been found significant and positive.

6.6.4 Brief description of mutual support group programme

The intervention protocol (see detailed description of the group programme and Tables 4.1 and 4.2 in Chapter 4) had been formulated to guide the mutual support group intervention, establish its consistency and ensure that the intervention group was organised in the prescribed manner. Family participants in the mutual support group had to attend 12 bi-weekly group sessions (over six months). Each group session lasted about two hours and the

time of the next meeting was decided by consensus of the group members during each group session. The support group was conducted in a room in one of the outpatient clinics under study by a group facilitator. The group facilitator was a registered psychiatric nurse being employed as a research assistant of this study, who previously received an intensive three-day training of group facilitation organised by the researcher. The objectives and activities of the training workshop were presented in Section 4.3 of Chapter 4 and Appendix 5.

The feasibility of the method and process of the mutual support group intervention and the facilitator training workshop was examined in the pilot study (see Chapter 4) and the trial run of the family support group was conducted with positive results. Content validity of the mutual support group programme was examined in the pilot study and described in Section 4.7.1 and a few changes to the programme were made in the main study, in the light of the findings of the pilot study as presented in Section 4.8 (Chapter 4).

In addition, the pilot study identified some preliminary themes and factors influencing the therapeutic process (see Appendix 6) and possibly the effectiveness of a mutual support group intervention for the family carers. These qualitative findings indicated the need for careful consideration of: group participants' perceived stages of group development, inhibitory factors influencing group and individual benefits, better facilitation on group ideology and consensus, and induction of some professional and social support outside group. The researcher, in discussion with the group facilitator, incorporated these changes into the intervention for the main study.

6.7 RESEARCH INSTRUMENTS FOR OUTCOME MEASUREMENTS

For outcome measurement, the subjects in the experimental and control groups were assessed with one pre-test (at recruitment) and three post-tests (at one week, six months & 12 months after intervention), using a set of questionnaires comprising: a Chinese version of four research instruments measuring family-related outcomes - perceived family burden, family functioning, perceived social support, and utilisation of family support service; two instruments measuring patients' specific level of functioning and symptom severity; and a demographic data sheet. The questionnaires required about 30-40 minutes to complete. The five psychosocial measures are attached as Appendix 7 and a detailed description of these instruments and their validity and reliability were given in the pilot study (Sections 5.3.5 and 5.5 of Chapter 5). Brief descriptions of these instruments, the demographic sheet and other additional measures on patient and family outcomes are presented below.

6.7.1 Family Burden Interview Schedule (FBIS)

This 25-item semi-structured FBIS designed by Pai and Kapur (1981) was used to assess families' burden of care in terms of six domains (2 – 6 items): effects on family finance, routine, leisure, interaction, physical health, and mental health. The items are rated on a three-point Likert type scale and the total scores range from 0 to 50, with higher scores indicating higher level of perceived burden. The Chinese version of the FBIS translated by the researcher in the pilot study and used in the present main study indicated adequate content validity (Content Validity Index = 95%), item equivalence with the English version (Intra-class correlation, ICC, between 0.80 to 0.89), internal consistency of the scale and individual items (Cronbach's alpha coefficients of 0.88 and 0.78 to 0.91, respectively). Satisfactory test-retest and inter-rater reliabilities (0.83 at two-week interval and ICC= 0.87 for overall scale) were indicated in the pilot study.

6.7.2 Family Assessment Device (FAD)

The 60-item FAD developed by Epstein et al. (1983) and translated into Chinese language by Sun and Cheung (1997) was used to measure multi-dimensions of family functioning among patients with severe mental illness. It is rated on a four-point Likert type scale (1 – 'strongly disagree' to 4 – 'strongly agree') along seven dimensions: problem solving, communication, roles, affective responsiveness, affective involvement, behavioural control, and general functioning and the total scores range from 7 to 28. The Chinese version demonstrated satisfactory content validity and high internal consistencies (Cronbach's alphas ranged from 0.77 to 0.90 for subscales, and 0.84 for overall scale) in the pilot study.

6.7.3 Six-item version of the Social Support Questionnaire (SSQ6)

This 6-item short form of the Social Support Questionnaire (SSQ) developed by Sarason et al. (1987) was used to measure the number of support persons (i.e. Number score) each family carer has as well as carer's satisfaction with the social support they received (i.e. Satisfaction score). The items are rated on a six-point Likert type scale (1 – 'very dissatisfied' to 6 – 'very satisfied) and the total scores range from zero to six. The Chinese version demonstrated satisfactory internal consistency (Cronbach's alpha coefficient = 0.94 for overall scale) and item equivalence with the original version (weighted kappas range from 0.48 to 0.67). The two subscales of the Chinese version indicated high internal consistencies (Cronbach's alphas = 0.90 and 0.91) in the pilot study.

6.7.4 Family Support Services Index (FSSI)

This checklist developed by Heller & Factor (1991) was used to measure the formal support service needs and their usage by families of a relative with mental illness. It was translated into Chinese language according to the available family support services for mentally ill people in Hong Kong by the researcher with consultation of an expert panel of mental health professionals. The modified Chinese index contains 16 items of local family supporting services and each item was rated for whether family needed the service and whether they were receiving that service (Yes/No responses). Satisfactory internal consistencies (Cronbach's alphas = 0.84 and 0.86) of the two subscales and inter-rater reliabilities (ICC = 0.81 and 0.85) were indicated in the pilot study.

6.7.5 Specific Level of Functioning Scale (SLOF)

This was a 43-item assessment scale developed by Schneider and Struening (1983) and modified by the Division of Mental Health Services in the State of New Jersey, in the USA. It comprises three functional areas of patients with schizophrenia: self-maintenance (consisting of physical functioning and personal care skills), social functioning (consisting of interpersonal relationships and social acceptability) and community living skills (consisting of activities of daily living and work skills). The items are rated on a five-point Likert scale and the total scores range from 43 - 210. Satisfactory internal consistencies of the Chinese version and its three subscales (Cronbach's alphas = 0.84 for overall scale and 0.79 to 0.89 for subscales) were also found in the pilot study.

6.7.6 Brief Psychiatric Rating Scale (BPRS)

The BPRS developed by Overall and Gorham (1962) consists of 18 global, clinically familiar symptom and behaviour constructs that span much of the range of manifest psychopathology and has been used effectively in clinical and research areas over the world for a few decades. The assessor rates each item of psychiatric symptom on a seven-point Likert scale (0 – 'not present' to 6 – 'extremely severe'). It demonstrates satisfactory internal consistency (Cronbach's alpha coefficients range 0.84 to 0.90), inter-rater reliability and construct and concurrent validities over a wide range of psychiatric patient populations and across cultures (Rhoades & Overall, 1988; Mueser, Curran & McHugo, 1997). In this study, this scale was rated by the psychiatrists who interviewed the patients when attending follow-up consultation at the outpatient clinics.

6.7.7 Demographic data sheet

Families were also asked to complete a demographic data sheet attached to the pre-test questionnaire, which included patient and family data as follows:

- Family carers' demographic characteristics: gender, age, education level, biological relationship with patient, and monthly household income;
- Patients' demographic characteristics: gender, age, education level, duration of mental illness, number of family members living with patient, present types and dosage of psychiatric medication, and overall mental condition in the past three months.

6.7.8 Other secondary outcome data

Additional sets of data not included in the questionnaire were reported bi-weekly by the experimental and control groups during the intervention period via telephone contacts with the research assistant (group facilitator for the experimental group) or the researcher (for the control group) and subsequently reported monthly by the groups over an one-year follow-up period. These data were written on a data record form and were summarised as pre-test data (baseline during recruitment) and data of three post-tests (one week, six months and 12 months after intervention). These data included:

- *Family Conflict Rating:* Frequency and severity of the episodes (1 - mild to 5 - very severe) of family conflicts in relation to patient care, the most frequently occurring subject of conflict and people involved, was reported by the family carers and recorded in a written form. This rating was found very useful to measure the levels of social adjustment of families of people with schizophrenia by Pakenham and Dadds (1987) in Australia. The average number of family conflicts per month was calculated at the pre-test (over 3 months before recruitment) and three post-tests (over 3 months before one week, 6 months and 12 months after intervention).
- *Length of patients' re-hospitalisation* in terms of days of psychiatric hospital stay, at the pre-test (over six months before intervention) and three post-tests (during the six-month intervention period and over the first six months and seven to 12 months after intervention), were checked from the patient records in the clinics.

6.8 INSTRUMENTS FOR PROCESS EVALUATION

For process evaluation of the mutual support group intervention, all the group sessions of the intervention were audio taped and the subjects in the experimental group were assessed

with semi-structured interviews within one to three weeks following the intervention. Details of the semi-structured interviews and the audiotapes of group sessions are described below:

6.8.1 Semi-structured interviews

One-to-one semi-structured interviews were conducted with all of the subjects in the experimental (mutual support) group. All of them were invited for interview because this might include the family carers with different levels of improvement in the intervention outcomes and degree of involvement and participation in the mutual support group. For instance, the families who did and those who did not demonstrate significant reduction in family burden at the first post-test, and those who had full (attended all 12 sessions) or less frequent attendance (less than six sessions) in group sessions. This sampling was designed to increase the likelihood of collecting diverse views from people (Parahoo, 1997), who had gained different levels of benefit from the group participation. The interviews were conducted within two weeks following the intervention at an interview room in the outpatient clinics. The researcher, instead of the research assistant, conducted all the interviews with these family carers in the mutual support group in order to avoid subjective bias from the group facilitator and minimise the desirable responses of the families under his facilitation. An interview guide had been designed to provide a tentative agenda for the interview (Appendix 9) and each interview lasted about one hour. The main purposes of the interviews were to: understand families' appraisals and feelings of group experience, identify their perceived benefits and constraints from group participation, and describe the group development and integrity and the individual and group level of change (i.e. to achieve the study objectives 3 in Section 6.2.1).

6.8.2 Audiotapes of group sessions

All 12 sessions of the three mutual support subgroups conducted in this trial were audio-recorded with consent from the participants. The recordings were reviewed together by the group facilitator and the researcher immediately after each group session and checked against the protocol for the proposed stages of group development. Specific attention of the review also focused on the process and content of discussions, information and experience sharing, and problem solving and coping skills learned by the family carers. They were also analysed for integrity of the group processes that might contribute to the therapeutic outcomes among the participants and compared with the interview data to emerge themes concerning the family carers' feelings and appraisals of the support group and their positive and negative changes during group participation (i.e. to achieve the study Objectives 3 in Section 6.2.1).

The facilitators collected additional data such as group attendance and non-verbal cues and behaviour during group meetings, for better understanding of the level of involvement of participants and mutual support among group members.

6.9 DATA COLLECTION PROCEDURES

The flow diagram (Figure 6.1) in Section 6.5, developed to adhere to the revised CONSORT statement (Altman et al., 2001), indicated the procedure of subject recruitment and the flow of subjects through each stage of the trial until the final data analysis. With ethical approval from the university and clinics under study and the permission for study access by the clinics, the eligible patients and their families were contacted by the research assistant at the clinics when they attended the follow-up appointment and were invited to participate in the study. They were informed of the purpose and procedures of the study, what would be expected of them as a study participant, and assured of their right to terminate participation at any time. Subjects in the experimental group were also asked for consent to allow group sessions to be tape-recorded for review and data analysis. Written consent (see Appendix 8) was obtained from both families and their patients.

With their consent, the family carers drew a sealed opaque envelope from the designated box and were allocated randomly to the experimental or control group according to the code indicated on the card within the envelope. The research assistant explained the group programme to the subjects of the experimental group and confirmed with them the time and venue of the first group session. After this subject recruitment procedure, the research assistant referred all the subjects in both the experimental and control groups immediately to the researcher. The researcher then collected the subjects' baseline data using the questionnaires.

The research assistant was trained to facilitate the mutual support group with a three-day workshop. During the six-month mutual support group, the research assistant conducted the group, collected data on group attendance and non-verbal cues and behaviour of group participants, and tape-recorded the group sessions for reviews and process evaluation. Data on family conflicts and patients' health status were collected via telephone follow-up of each family bi-weekly over the intervention period. Reviews of the audio-taped group sessions, and discussion between the researcher and the group facilitator about the group progress and related difficulties, were undertaken between the group sessions.

Following the interventions, the researcher administered the first post-test questionnaire to all the study subjects from one to two weeks. Upon completion of the post-

test measurement, the researcher carried out a semi-structured interview with 20 of the support group participants who gave their consent, and the interviews were audio taped.

Telephone follow-up of the study groups was conducted monthly by the research assistant, in which the data on family conflicts and patients' medication were obtained from the family carers, for 12 months. The periods of patients' re-hospitalisations and the BPRS scores (measured by the attending psychiatrist) were checked in their OPD records every two months, over the 18-month study period. The researcher administered the second and third post-tests for the two groups at six and 12 months following the interventions, respectively.

6.10 DATA ANALYSIS PROCEDURES

The procedures of statistical analyses of the quantitative data collected in this clinical trial and content analysis of the interview and group session data are presented in detail as follows:

6.10.1 Analysis of quantitative data

The data in the demographic data sheet and the pre-test and three post-tests measurement scores of the experimental and control group were analysed using descriptive and inferential statistics. Statistical Package for Social Sciences (SPSS) for Windows version 13.0 was used for the statistical analysis. The data analyses for the outcome variables in this trial were designed on intention-to-treat basis; thus, all of the 76 subjects' data were used in the final data analysis, without any subject who was withdrawn from the study before the pre-test or who was found incompatible with the sample criteria before intervention (Montori & Guyatt, 2001). The data analysis strategies for this study are summarised in Table 6.1.

Table 6.1 Strategies for analyses of quantitative data in the main study

Purpose/hypothesis	Variables	Instrument	Statistical tests
To describe families' and patients' characteristics in experimental and control group.	• Family carers' age, monthly household income, number of family members living with patient; • Patients' age and duration of mental illness (interval or ratio data)	Demographic data sheet	• Means, standard deviations, ranges (minimum and maximum values)

	• Family carers' gender, education level, biological relationship with patient; • Patients' gender, education level, present medication and its dosage, and mental condition in last 3 months (ordinal / nominal data)	Demographic data sheet	• Frequencies and percentages
There is no statistical significant difference in demographic characteristics between the experimental and control group.	• Family carers' age, monthly household income, number of family members living with patient; Patients' age and duration of mental illness (interval or ratio) • Families' and Patients' educational level; Patients' mental condition and present medication dosage (ordinal) • Families and patients' gender; Relationship with patient (nominal)	Demographic data sheet	• Unpaired t-test (two-tailed) • Mann-Whitney U-test (if number of subjects are not less than 20) • Chi-square test
There is no statistical significant difference on the mean scores of the primary outcome (FBIS) and four statistically correlated secondary outcomes between the experimental and control group in response to treatments.	• Mean scores of the FBIS, FAD, SSQ6 – number of support persons, SSQ6 – level of satisfaction, and SLOF in one pre-test and three post-test measurements	FBIS, FAD, SSQ6 – number of support persons, SSQ6 - level of satisfaction, and SLOF within the questionnaire	• Repeated-measures multivariate analysis of variance (MANOVA) for comparison of mean scores of the five measures within and between the two study groups and over time; • Roy-Bargmann step-down analysis with a series of univariate analysis of covariance tests using the higher priority dependent variables from these measures as covariates • Post hoc multiple comparison, Scheffé's test, for examining which mean value exceeded the minimum significant difference.

There is no statistical significant difference on mean scores of the FSSI between the experimental and control group in response to treatments.	• Mean scores of the FSSI – services in need and those receiving in pre-test and post-tests	FSSI within the questionnaire	• Repeated measures ANOVAs for the two subscales of the dependent variable (mean scores of the FSSI– services in need and FSSI- services receiving) were used and group status serves as one factor and time of measurement is the second factor; • For the FSSI, post hoc multiple comparisons, Scheffé's test, for examining which mean value exceeded the minimum significant difference.
There is no statistical significant difference on demographic variables between three experimental (mutual support) subgroups at baseline.	• Demographic variables of the experimental sub-groups	• Demograph-ic data sheet	• ANOVA (interval or ratio), • Kruskal-Wallis test (ordinal), or • Chi-square test (nominal).
There is no significant differences on pre and post-test mean scores of the psychosocial outcomes between three mutual support subgroups	• Pre-test and three post-test mean scores of the primary and secondary outcome measures of the subgroups	• Five scales in question-naire	• Repeated-measures ANOVA for each independent variable
To compare the differences on amount of family conflicts, BPRS score and length of patients' hospitalisations between experimental and control group.	• Average amount of family conflicts per month and length of patients' hospitalisation (in days) every six months (over six months before intervention, during intervention period, and six and 12 months after intervention) • BPRS scores at pre-test and 3 post-tests	• Telephone interviews with each family monthly or bi-monthly and recording on a data form • BPRS in the OPD record	• Repeated-measures ANOVA

To test the three null hypotheses stated in Section 6.2.2, the preliminary assumptions for multivariate and univariate analyses of all the study outcome variables were checked and decisions were made for using repeated measures multivariate or univariate analysis of variance test for each outcome variable of this study. These are described as below:

Testing the assumptions and decision for univariate and multivariate analyses

Preliminary assumption testing of the study variables was conducted for univariate and multivariate outliers, normality, linearity, homogeneity of variances, and multi-collinearity (Stevens, 2002), with no serious violation noted. Power of the multivariate analysis used for these outcome measures was maintained by having equal sample size between the two groups and no missing or incomplete data in this study. The reasonably straight line of the normal probability plots, non-clustering of points around zero in the detrended normal probability plots, and the non-significant results of the Kolmogorov-Smirnov statistic (p values ranged from 0.09 to 0.21) indicated univariate normality of all outcome variables used in the study (Tabachnick & Fidell, 2001). The box-plots of the outcome variable scores indicated no extreme points, but only one outlier in the FBIS (i.e. it was 13) and FAD (i.e. it was 21). These two outliers were within the range of possible scores for the two scales (score range 13 – 24 for the FBIS and 15 – 21 for the FAD), and considered to remain in the data analysis.

At the baseline measurement, there were significant correlations between the primary outcome measure – Family Burden Interview Schedule (FBIS) and the other four secondary outcome variables including Family Assessment Device (FAD), Six-item Social Support Questionnaire (SSQ6) – number of support persons, SSQ6 – level of satisfaction, and Specific Level of Functioning scale (SLOF) (Pearson's correlation coefficient $r = 0.44 – 0.87$, $p < 0.0005$). Results of the correlations between all the study variables at baseline measurement are presented in Section 7.3 (Chapter 7) and Appendix 12. In addition, further checking of the inter-relationships of the mean scores of these measures at the three post-tests also found statistically significant correlations between all of them ($r = 0.46 – 0.85$, $p < 0.0005$). Thus, the significantly correlated outcome measures including FBIS, FAD, SSQ6– number of support persons, SSQ6– level of satisfaction, and SLOF were analysed together to examine the composite effect of intervention between groups and over time, using repeated-measures multivariate analysis of variance (MANOVA), and followed by Roy-Bargmann step-down analysis with a series of univariate analysis of covariance (ANCOVA) tests using the higher priority dependent variables from these measures as covariates was then performed to identify the independent effect of each of these five variables (Tabachnick & Fidell,

2001). This analysis protected the inflated Type I error due to multiple univariate testing by an appropriate adjustment of the alpha value.

The Mahalanobis distance values, which indicate any strange pattern of scores across the five correlated outcome variables in each group of participants used in multivariate analysis, were 19.2 for the mutual support group and 19.7 for the standard care group (compared with the critical Chi-square value of 20.52, df= 5, criterion alpha= 0.001) and thus indicated no multivariate outliers in the two groups. Generating the scatter-plots assessed linearity of all pairs of these five variables in each study group and the results that the points scattered around a straight line in each pair of these variables indicated a satisfactory linear relationship between the two variables. The degree to which the five dependent variables were correlated provided information as to the independence of behaviours. Pooled within-cell correlations, adjusted for group and time, as produced by SPSS MANOVA through PRINT= ERROR(COR), are indicated in Table 6.2. All correlations among the five variables were in excess of 0.30 as step-down analysis was appropriate (Tabnachnick & Fidell, 2001). As Roy-Bargmann step-down analysis was planned to assess the importance of individual outcome measures after MANOVA, tests of homogeneity of regression was performed for each variable. The F values were non-significant ($p > 0.05$) and homogeneity of regression was established for all components of the step-down analysis (Tabachnick & Fidell, 2001). The very sensitive Box's M test for homogeneity of dispersion matrices produced $F(210, 16735) = 1.08$, $p > 0.01$, confirming homogeneity of variance-covariance matrices. The log-determinant of the pooled within-cells correlation matrix was found to be 0.53, yielding a determinant of 1.69. This was sufficiently different from zero that multi-collinearity was not a problem (Stevens, 2002).

A repeated measures MANOVA test was thus performed on these five statistically correlated variables. Independent variables were group (mutual support and standard care) and time (baseline and one week, six months, and 12 months after intervention). With significant main effects in MANOVA, the univarate analyses of variance and step-down analysis of the five prioritised outcome variables were performed and the SPSS outputs are also presented in Appendix 10. In the step-down analysis, each outcome variable was analysed, in turn, with high priority dependent variables (FAD, SLOF, SSQ6 - number of support persons) treated as covariates and with the highest priority dependent variable (i.e. FBIS) tested in a univariate ANOVA.

Table 6.2 Pooled within-cell correlations among five outcome measures

WITHIN+RESIDUAL Correlations with Std. Devs. on Diagonal

	FBIS	SLOF	FAD	SUPRT	SATSUP
FBIS	10.530				
SLOF	.466	14.426			
FAD	.455	.687	1.870		
SSQ6- No. of Support persons	.478	.355	.372	1.087	
SSQ6- Support Satisfaction	.549	.509	.431	.772	.930

However, the repeated measures between-within subjects ANOVA (group x time) tests were conducted to compare the effects of the interventions between the two study groups over time and the 'group by time' interaction on the other outcome variables (i.e. the FSSI, length of patients' re-hospitalisation, average amount of family conflicts, and BPRS). These variables indicated no statistically significant relationships with each other at baseline measurement as presented in Section 7.3 of Chapter 7 and Appendix 13. With consideration to multiple testing using ANOVA tests, Bonferroni's corrected p value of 0.01 (i.e. 0.05 divided by 5) was used to minimise the Type I error of the statistical results.

Post-hoc comparisons using the Scheffé's comparison test to evaluate the pair-wise mean differences of each variable indicated significant difference between the two groups over the study period in the multivariate and univariate analyses of variance. The Scheffé's comparison is the most flexible and rigorous of the post-hoc multiple comparison tests and thus strongly protects against the Type I error (Portney & Watkins, 2000).

Moreover, the socio-demographic characteristics of the families and their patients at baseline measurement and the mean scores of their psychosocial outcomes over the study period were compared between the three subgroups of the mutual support group used in the study. The purpose of this comparison was to ensure the homogeneity of the subjects in the three subgroups at baseline and any differences in those psychosocial outcomes over the 12-month follow-up period. If any differences were found in these variables, the possible reasons should be carefully examined by reviewing the audiotapes of the group sessions and

additional statistical analysis of any potential covariant effect to the results of the study outcomes should be considered.

Data analysis of other secondary outcome variables

Data on group attendance, attrition rate (failure to complete the intervention and/or follow-up) and changes in types and dosages of neuroleptic medications of the experimental and control groups were summarised using descriptive statistics and compared between the two groups using a two-tailed independent-samples t-test (interval or ratio data) or Chi-square test (categorical or ordinal data).

Clinical significant change in the primary outcome measure

In addition to identifying any statistically significant differences within the mutual support group and between the two study groups on the study variables, clinically significant change in the primary and secondary outcome measures was also assessed within and between groups. This was determined using Jacobson and Traux's (1991) criteria for clinical significant change, in which the most stringent and conservative cut-off point for such change is a client's post-intervention and follow-up scores extending to two standard deviations above the pre-intervention mean score (in the direction of functionality). This cut-off point was chosen also because the norm of caregiver burden had not been reported adequately in the previous clinical trials, and a test of statistical significance only offered limited insight into the clinical benefit of the intervention for each individual client (Jacobson et al., 1999). In order to ensure that the pre-intervention mean score and standard deviation could represent that of the patient population under study, they were checked against the results of the pilot study on family burden and other psychosocial variables among 185 Chinese families of outpatients with schizophrenia (see Table 5.4 in Chapter 5); and the two sets of results were found very similar. The analysis of clinically significant change provided information on variability of outcome within each group (i.e. proportion of subjects who became well functioning or normal, the percentage of subjects who improved but did not recover, and those who remained unchanged or deteriorated in each treatment condition), and was considered as one way of determining the practical importance of statistically significant differences between groups (Speer, 1992).

The Reliable Change Index (RCI), as a second criterion for clinically significant change and, like a confidence interval of such change, was also calculated to ensure that the degree of change was of sufficient magnitude to exceed the margin of measurement error

(Jacobson & Truax, 1991). The Index involves the pre and post-test treatment score difference of an individual client being divided by the standard error of the differences between the two test scores. Jacobson et al. (1999) suggest that if the RCI exceeds 1.96, the probability is less than 0.05 that the mean difference occurred by chance and the client is considered to have significantly improved or changed to a more functional state.

6.10.2 Analysis of qualitative data

Interview data (20 interview scripts) and the three sets of 12 group meeting tape-records for the three mutual support subgroups were transcribed into Cantonese and then translated into English by the researcher. The first three transcripts of interview and group sessions were transcribed and translated by both the researcher and one bilingual research assistant (who was trained in qualitative research methods) independently, and compared for accuracy of transcription and translation in terms of the conceptual or literal meaning of statements. Any differences between the transcription and the translation were examined and discussed by the researcher and the research assistant to ensure reliability of further transcription, and the agreed amendments were made. Translated data were analysed using content analysis (Morse & Field, 1995). Interview scripts were used as a starting point for coding and establishing themes. Translated group sessions provided rich data on the group process and stages of group development, and confirmed or refuted the themes that emerged from the interview data. The researcher and the research assistant then identified themes from all of the 20 interview scripts, independently, and checked the coding reliability (i.e. > 92% of agreement in coding of the data as suggested by Morse, Penrod and Hcpcey, 2000), before categorising the interview data into themes. Finally, these themes were reorganised, contrasted and mapped to establish the therapeutic mechanisms of the mutual support, by making interpretation and providing explanation of the possible relationships between these identified themes.

To maintain objectivity and credibility in the interpretation of data, the researcher attempted to suppress his preconceived attitudes and expectations regarding support group intervention, as suggested by Morse (1997), so that the reality described by the study subjects could be interpreted accurately. Tape records were referred to where clarification of the theme was required. Meaningful entities relating to the understanding of the family appraisals of the group process were identified including:

the feelings and attitudes towards the support group and fellow group members, perceived benefits and difficulties from group participation, reasons for continuation or discontinuation of participation, and development of the support group as well as the factors influencing this. Preliminary themes were validated and checked with the audio taped group sessions in order to identify similarities between them and find contradicting evidence. Theme identifying, matching and condensation were then performed according to a procedure advocated by Miles and Huberman (1994), who suggest collating in-depth information and accommodating the diversity of experiences and feelings of each informant. This approach consists of six stages of analysis:

(a) Getting familiar with the diversity of the verbatim data collected and affixing codes and remarks to each transcript;

(b) Sorting and sifting through the codes and interview data to identify similarities, differences and patterns between the codes and noting the recurrent themes emerging from transcripts;

(c) Elaborating a set of generalisations that cover the consistencies discerned in the interview data and field notes (interview and group session data in this study);

(d) Isolating the patterns and clustering commonalities and differences between the themes and creating a thematic index to all transcripts;

(e) Reorganising, contrasting and mapping the categories and themes identified, making interpretations and providing explanations; and

(f) Finalising the materials, re-examining the data if necessary, and drawing conclusions.

A worked example of qualitative data analysis indicating the steps in the six-stage procedure recommended by Miles and Huberman (1994) is attached in Appendix 11. Some extracts from the interview and group session data were used verbatim to illustrate the process of identifying, mapping, condensing, and finalising the themes and categories in relation to the perceived therapeutic elements of the mutual support group. The worked example also indicated one therapeutic mechanism of the mutual support group, which was generated by repeating the steps (e) and (f) - reorganising and mapping the themes and categories identified, making interpretation of the relationships between them, re-examining the data, and drawing the conclusions. The four therapeutic mechanisms of the support group identified are presented in Chapter 8.

6.11 ISSUES OF RELIABILITY AND VALIDITY FOR THE RCT

This study was a randomised controlled trial (RCT) or effectiveness research that was aimed at answering a direct but important question: which of the two interventions achieves relatively the greatest treatment effect or the best outcomes being evaluated. For a clinical trial involving human beings in their social environment, as in this study, the real-world research environment is generally beyond the control of the researcher and so is unlike in a true experiment conducted in a laboratory setting (Matthews, 2000). As suggested by Wolff (2000), when an intervention is implemented and its effects on study subjects evaluated longitudinally with unexpected and uncontrolled changes in the external environment, external and confounding variables may occur to influence the study outcomes, and induce threats to internal and external validity of the study. In view of these difficulties, the following description sets out how the methodological challenges involved in conducting a RCT in a clinical setting as in this study were managed.

6.11.1 A precisely defined intervention protocol and its adherence

The intervention protocol defined what was to be provided for or administered to the study sample and when each procedure of the intervention was to take place. Altman et al. (2001) pointed out that treatment protocols or guidelines reported in previous controlled trials and other intervention studies vary in their degree of clarity and comprehensiveness. In order to better standardise the mutual support group intervention used in this study and to monitor it for adherence and for purposes of validity and replication of the findings, the intervention protocol of the support group was clearly defined and documented as precisely as possible, as described in Chapter 4. This protocol could reduce the degree of ambiguity and increase the reliability of measuring the effect of the intervention on study participants (Begg et al., 1996). It also informed others interested in this topic clearly of the structure and degree of the intervention (dose) used. Similarly, the intervention received by the standard care (control) group was also clearly identified and monitored over the six-month intervention period. The group facilitator assisted and encouraged the development of the mutual support group. Adherence of the group facilitator to the protocol for the support group was assured through a three-day training workshop for the facilitator prior to the start of the trial and bi-weekly review of the group process and the research nurse's facilitation style by the responsible researcher, who was an experienced group worker.

In spite of the hard-to-model dynamic nature of the mutual support group intervention, frequent reference to the structured intervention protocol and regular review throughout the intervention period, helped to ensure good standardisation and adherence to the intervention evaluated in this study. This was clear from the review meetings between the group facilitator and the researcher, which demonstrated a high degree of adherence of the group facilitator and the peer leaders to the protocol throughout the study. Good standardisation of the intervention sought to assure an optimal combined effect of all of its components in creating an interactive social support process among the group participants.

Experimenter effect produced by the personal characteristics of the group facilitator and subjective biases of the researcher to the success of the group intervention is known to affect the behaviour and performance of the subjects in the experimental and control groups (Yalom, 1995; Polit & Hungler, 1999), and thus induce threats to external validity. This threat to external validity could not be fully avoided but attempts were made to minimise their effect by standardisation of the study and intervention procedures, and accurate and consistent implementation of the intervention according to the protocol. The researcher who was blinded to the group allocation of the subjects undertook all data collection from the study subjects independently. This might reduce biases in administration of the questionnaires and avoid embarrassment or desirable responses to the group facilitator during the qualitative interview.

To avoid different levels of skills for group facilitation, the simplest staffing arrangement for implementation of the group intervention was used in this study. This involved a single facilitator (a registered psychiatric nurse) who was trained to a protocol in delivering the mutual support group intervention. In addition, the role of the facilitator in the group intervention used in this study was only to encourage and assist the development of mutual help and support. The group participants themselves took an active role in sharing information and experiences, searching for appropriate information from resources outside the group, and sought advice from health professionals (Wilson, 1995). One trained competent group facilitator was found effective in delivering the group intervention in this trial.

6.11.2 Study sample representativeness and its equivalence

One aspect of the external validity of this trial concerned the adequacy of sampling design. If the characteristics of the sample in this study were representative of those of the population, then generalisation could be achieved. The precise inclusion criteria (see Section 6.4.2) for selection the sample in this study sought to reduce ambiguity in the

definition of the population from which the sample was drawn. The cut-off point of five years duration of illness for inclusion in the sample shifted the focus of the intervention to a relatively early and acute stage of schizophrenia in which the health needs of patients and families would be different from those in the chronic stage of the illness (Pharoah et al., 2001). It is acknowledged that excluding more chronic patients or patients with dual diagnoses from possible selection of study subjects may reduce the generalisability of the findings to the population of Chinese patients with schizophrenia.

Whilst the accessible population of the two study outpatient clinics might not be fully representative of all family carers of Chinese patients with schizophrenia in Hong Kong, this consisted of more than 10% of the total population of patients with schizophrenia. Moreover, with a small sample size (i.e. 38 in each study group), it was quite possible to have unequal assignment of patients such that one group had more seriously ill subjects than the other. In spite of this, the randomised sampling with adequate power estimation and comparison of sample characteristics to the target population in Hong Kong increased the generalisability of the results to the Hong Kong Chinese families of people with schizophrenia. Selection bias was assessed by comparing the salient characteristics of all the families caring for a relative with schizophrenia in Hong Kong to those families who voluntarily participated in the study. As suggested by Wolff (2000), these characteristics were those that related to behaviours targeted by the intervention in this study, including patients' medication and mental condition, number of family members living with patient, treatment compliance, and any other family interventions received.

6.11.3 Equivalent trial environment and double blinding

The patients and their families in this study were living in the community in which confounding external effects such as mental health service policy changes could not be controlled. Thus, some changes in the subject condition during the study period might not be the same between the experimental and control group over the 18-month study period. However, through the randomisation procedure and taking into consideration the differences in clinic and subject characteristics by stratified sampling in the study, the characteristics of the subjects were similar between the two groups at baseline. Monitoring of the subjects' social environment such as other family supporting services received, interactions between subjects in both groups, changes in patients' mental condition and medications, and clinic staff being blinded to study participation, took into account effects of some external events that took

place concurrently with the independent variable throughout the study period (Polit & Hungler, 1999), and these extraneous variables were also taken into consideration when analysing the study outcomes.

The ideal of a double blind study could not be achieved because the subjects in experimental and control group were aware of the intervention they were receiving and the study procedure (Bailer & Mosteller, 1992). This knowledge about the treatment might contribute to a placebo or socially desirable effect if a participant believed that one of the interventions was more useful or superior to the other. In order to minimise the placebo effect, the group facilitator and researcher did not show that they had any preconceived ideas that the mutual support group would be more effective than the standard care (psychiatric outpatient) service during recruitment and group facilitation. The administration of pre and post-test measures was conducted on an individual basis by the researcher who was blinded to the group allocation of the subjects. The clinic staff were also blinded to the subjects' participation in this study (i.e. the subjects were asked not to inform the clinic staff about their participation in the study).

6.11.4 Other issues of reliability and validity for the RCT

Two other issues of reliability and validity of RCT-based effectiveness research were carefully considered. First, the subjectivity of the researcher in administering the research instruments might also have exerted possible bias to the measurements. This was avoided in this study by the researcher, who administered the instruments, being blinded to the study group allocation of the subjects. Pilot testing of the test-retest and inter-rater reliabilities of the research instruments also sought to minimise the instrumentation effects, that is the differences in the accuracy of repeated administration of the measuring tools (Polit & Hungler, 1999). The Chinese version of the research instruments were pilot tested to ensure satisfactory reliability and validity, specifically internal consistency, content and construct validity, prior to their use in the main study.

Second, mortality, which refers to the threat that arises from differential attrition from the groups being compared (Polit & Hungler, 1999), could have threatened the internal validity of this study. The group facilitator monitored attrition and those who might be difficult to follow-up during the intervention period, by bi-weekly telephone contacts during the intervention and monthly over the 12-month follow-up period. The researcher also monitored the subjects' attrition following the interventions and analysed the attrition bias to

the outcomes of the two study groups. The analysis of attrition bias was typically achieved through a comparison of those who did and did not complete the study with regard to initial measures of the dependent variable or other characteristics measured at the pre-test. Since data analysis for this trial had been designed on intention-to-treat basis, all subjects' data were used in the final analysis, with the exception of those who were withdrawn from the study before the pre-test or who were found incompatible with the sample criteria before the interventions (Gibaldi & Sullivan, 1997; Montori & Guyatt, 2001). The effects of high attrition of or unequal mortality rate between the experimental and control groups are considered in the discussion of the results in Chapter 9 (Section 9.2).

6.12 ENSURING RIGOR OF THE INTERVIEW AND TAPE RECORDED DATA

This section considers threats to the credibility of findings from the qualitative data and how these were managed. .

6.12.1 Interview and tape recording of group sessions as data collection method

Unstructured or loosely structured self-report methods offer the researcher flexibility in gathering information from study participants on their perceptions of and experiences in an intervention. When these methods are used, the researcher generally does not have a specific set of questions that will be asked in a specific order. This allows the respondents to tell their stories in a narrative fashion but they are encouraged also to define the important dimensions of the phenomenon, which may not be relevant or focused on the study's a priori notions of specificity or importance (Munhall, 2001). In the present study, a specific objective was to identify family carers' perceptions of the benefits obtained from and difficulties experienced in the mutual support group intervention. Therefore, a semi-structured interview (with a tentative interview agenda or list of questions to be covered with each respondent) was employed to ensure that the specific set of questions or topics appropriate and important to the study objective (Objective 3 in Section 6.2.1) could be adequately covered. This data collection method is widely and effectively used to obtain more in-depth and rich data from each study participant whilst in this study it was also easier to focus on obtaining the viewpoints of all family carers about the therapeutic components and difficulties experienced in the group intervention.

Nevertheless, this open-ended method of interviewing meant inevitably that the more articulate relatives contributed substantially more to the data set than those who were less forthright with their views. It was important for the interviewer (the researcher) in this study to be experienced in interviewing and to encourage the family carers to talk freely about all the topics in the interview guide, elaborate the viewpoints in detail and tape record all their responses. The researcher ascertained from each family carer the most convenient time and venue for them to attend the interviews. In order to facilitate the carers' participation in the interviews, the researcher had to arrange temporary care for the patient during the interview if needed.

The presence of an interviewer to obtain the information from the family carers about the effects of the intervention on them and interactions between the interviewer (researcher) and interviewees (carers) might induce interviewer bias and affect the family carers' responses. In addition, the interviewer's involvement in the study design and intervention and his preoccupation with the potential positive effect of the mutual support group to the family carers might also induce subjective bias to the meaning of the interview data. To maintain objectivity and credibility in the collection and interpretation of interview data, the researcher attempted to suppress his preconceived attitude and expectations regarding support group intervention, as suggested by Morse (1997), so that the reality described by the study subjects could be interpreted accurately. Nevertheless, the researcher instead of the research assistant conducted all the interviews with these family carers in the mutual support group in order to avoid subjective bias from the group facilitator and minimise the desirable responses of the families under his facilitation. In addition, all 12 mutual support group sessions were audio taped to provide detailed and full data on the group process and its development, and confirmed or refuted the responses and themes that emerged from the interview data. The research assistant also checked the researcher's interpretation of the interview and group session data in the process of data analysis.

Whilst there were threats to the validity of the interview data the semi-structured interviews used in this study increased the validity of the findings through: inviting all the group participants to be interviewed; offering some protection against ambiguous questions since any misunderstanding could be clarified by the researcher; and providing an opportunity for respondents to give in-depth accounts of their experiences of participation in the mutual support group. Nevertheless, the response

rate of the interview in this study was not high (n = 20, 53%), mainly because seven of them did not have the time or were very busy and physically exhausted from work over the period of interviews (i.e. 2-4 weeks after the intervention completed).

6.12.2 Purposive sample of support group participants

Two recurrent but important questions concerning the sources of data in a qualitative research are the matters of sample size and recruitment of appropriate sample (Morse, 1997), ensuring relevant and sufficient data to answer the research questions. In studies that use a single source of data such as a one-time interview as such in this study, one would expect to see larger numbers of informants included in the design. In this study, all 38 family carers participating in the mutual support group were invited to be the sample for the semi-structured interview. The interviews were scheduled at the earliest time possible (1-2 weeks) following the last group session so that the family carers could still be able to remember clearly their experiences in and the process of the group participation. The interview data collected from the family carers indicated that there was a saturation of or redundancy in the data; that is, the researcher found that no new data were emerging when analysing the last few interview scripts. This is the common rule of thumb of ensuring adequacy of the database for the research question, as suggested by Miles and Huberman (1994) and Munhall (2001).

In addition, as shown in Chapter 8, the socio-demographic characteristics of the 20 interviewees and the remaining 18 carers who refused to be interviewed were examined. There were no any significant statistical differences between the characteristics of the interviewees and the non-respondents and thus the interview data from the 20 carers might be representative of all 38 group participants in this study.

6.12.3 Issues of reliability for content analysis

Besides the data collection methods used and the appropriateness of the sample recruited, the reliability of the findings of a qualitative research, similar to the interviews and audio taped group sessions conducted in this study, also rely much on the rigour of data analysis method and procedures. In this study, thematic analysis was used to identify main themes and meaningful entities that emerged from a large set of the interview (20 one-hour interviews) and group session (three sets of 12 support group sessions) data. To ensure the content and semantic equivalence of the interview

and group session transcripts with the original tape-records, appropriate transcription and translation of the audio tape-records are important. In order to ensure the accuracy and reliability of the transcription done by the researcher, the first three transcripts of interviews and group sessions were transcribed and translated by both the researcher and one bilingual research assistant independently. They compared the two sets of transcripts for accuracy of transcription and translation in terms of the conceptual or literal meaning of statements. Any differences between the transcription and the translation were discussed and amended with their agreement in order to ensure reliability of further transcription.

The researcher and the research assistant then identified themes from all of the 20 interview scripts (and all group sessions), independently, and checked the coding reliability (percentage of agreement in coding of the data) before finalising the themes for further categorisation, as suggested by Morse et al. (2000). To maintain objectivity and credibility in the interpretation of interview and group session data, the researcher held in check his preconceived attitude and expectations regarding the mutual support group and referred to the tape records in case clarification and confirmation of the themes identified was required, as suggested by Morse (1997), so that the reality described by the participants could be interpreted accurately. Finally, a standardised procedure advocated by Miles and Huberman (1994) was used to perform theme matching and condensation in order to collate related concepts of therapeutic mechanisms of the support group, and summarise the themes precisely and systematically.

6.13 ETHICAL CONSIDERATIONS

Ethical approval of the study and permission to access and contact the study subjects and their personal data were obtained from the Clinical Research Ethical Committee at the Chinese University of Hong Kong and the Hospital Chief Executives of the two clinics under study, respectively. The approval letter from the Research Ethics Committee is attached in Appendix 12. Three major ethical issues raised by the study are as follows:

6.13.1 Informed consent and voluntary participation

Recruitment of patients and their family carers is described in detail in Section 6.5. Eligible patients and their family carers were invited to participate in the study by the

research assistant with full explanation of the study purpose and procedure. They were also informed verbally of the possible benefits and risks to study subjects and of their right to terminate participation at any time. They were also assured that their data in the study would be kept confidential and that their identity would not be revealed in any documents and reports. Written consent (see Appendix 8) was then obtained on a voluntarily basis and sufficient time given for the patients and their family carers to ask questions about the study and have these answered. Families were asked to consent to be interviewed and for group sessions to be audio-taped if they were recruited to the treatment group in the study. They were allowed to terminate participation in the study if they wished without giving an explanation, or when another group psychotherapy or family therapy was prescribed by an attending psychiatrist during the intervention period.

6.13.2 Confidentiality

Subjects and clinic staff were assured that all data referring to the study would be kept in a data file accessible to the researcher only. Personal identity of the subjects or clinics was represented by a code number and not revealed in any research report or documentation. The clinic staff were blinded to the subjects' participation of the study and therefore they did not have any subjective bias and the subjects were not deprived of any routine service provided by the outpatient clinics.

6.13.3 Benefits

This study had potential benefits to any primary carer of a relative with schizophrenia. Mutual support and learning from other group members in a similar situation and with similar concerns might help them relieve their feelings of distress and improve their skills of patient care. Although some health professionals in Hong Kong were running similar types of family/patient support groups, those groups had been on an irregular basis and not well-structured and organised. The findings of the study might improve the family support of outpatients with schizophrenia. However, there was no monetary reward or return during their participation in the support group or the study. The control group would then be given the opportunity to participate in another mutual support group on completion of the study if they wanted, and if the findings of this study were positive.

CHAPTER 7 EFFECTIVENESS OF THE MUTUAL SUPPORT GROUP INTERVENTION

7.1 INTRODUCTION

This Chapter presents the results of the analyses of data collected to investigate the effectiveness of the mutual support group intervention; thus the data presented here addressed Objectives 1 and 2 of the present study, which are listed in Section 6.2.1 of Chapter 6. Section 7.2 summarises the socio-demographic characteristics of the participants (the outpatients with schizophrenia and their family carers) in the mutual support and control groups at baseline measurement and presents the results of the comparisons of these characteristics between the two study groups and those who refused or were unable to participate in the study. The mean scores of the outcome measures at baseline and the three post-tests and comparison within and between the two study groups are presented in Section 7.3. Finally, Section 7.4 reports the clinical significance of changes in the primary (family burden) and secondary outcomes of the study at three post-tests as compared to the baseline measurement and comparison of these changes between the two study groups.

7.2 DEMOGRAPHIC CHARACTERISTICS OF FAMILY CARERS AND PATIENTS AT BASELINE

As indicated in the flow diagram summarised in the trial design (Figure 6.1 in Section 6.5.3 of Chapter 6) according to recommendations from the CONSORT statement (Altman et al., 2001), 200 families of outpatients suffering from schizophrenia fulfilled the study criteria (i.e. 20.3% of patients with schizophrenia in the two clinics) and were eligible for inclusion in this study. Of these, 130 consented to be the participants in this study. Thus, 70 eligible families (35.0%) were excluded from this initial recruitment process because these families either refused to participate (n= 35), did not have time to attend the group (n= 25), or were engaged in another family therapy programme (n= 10). Finally, a total of 76 families were selected randomly from the list of eligible participants and assigned randomly to either the mutual support group or the control group (i.e. 38 subjects in each group). The remaining eligible families (n= 54) were put on a waiting list for a future group programme or referred to another family therapy if they requested.

Four family carers in the mutual support group were considered to have discontinued treatment because they failed to attend a minimum of seven group sessions. Reasons given were: time constraints due to unpredictable working hours and high demand of household chores; clashes with other family activities; and not having established a trusting relationship and openness with other group members. Mean and median attendance at group sessions by all participants in the treatment group was 9.0 (SD= 1.1) and 9.2 (range 4 - 12), respectively. One participant in the standard care group did not complete the third post-test and so the third post-test data were determined by the average of the previous three sets of scores; this is an acceptable procedure for completing missing data for drop-outs (Bailer & Mosteller, 1992; Matthews, 2000), where a substantial proportion of previous data are available. Hence, all data of the 76 participants were included in the final data analysis.

The socio-demographic characteristics of the family carers in the two study groups and those 124 eligible family carers not recruited in this study are summarised in Table 7.1. This table shows that all of the family characteristics at baseline measurement were very similar between the support group, standard care group and those eligible family carers who were not recruited. There were no significant statistical differences in these demographic characteristics between the three groups, using analysis of variance (F test, df= 2,196) or Kruskal-Wallis test by ranks (H statistic, df= 2). Within the three groups, more than half of the primary carers were female (52.6% - 57.9%) and they were all ethnic Chinese (n=60 or 79.0% were Hong Kong in-born and the remaining 16 were mainland China immigrants). Their mean age ranged from 34.9 to 37.1 years (SD= 11.6 – 12.9), with a wide age range from 20 to 62 years. About two-thirds of them in the three groups were aged between 20-39 years (65.8% - 72.6%) and had a satisfactory education level (65.8% - 73.7% completed at least secondary school education). Over 90% were closely and/or blood related to the patient in their family – typically a spouse, parent or child. The average monthly household income of the three groups (HKD 10,100 – 11,600) was within the median range of monthly household income in Hong Kong (HKD 7,500 – 13,000) in 2003 (Census & Statistics Department, 2004). Over 90% of the families had two to four family members living with the patient. In addition, for the mutual support and control groups, the average contact time with the patient was 3.1 (SD= 1.2) and 3.2 (SD= 1.3) hours per day, respectively. The average severity of family conflicts was moderate in

the mutual support (M= 3.0 per week, SD= 0.6) and control (M= 3.1 per week, SD= 0.7) groups at baseline; and it had no significant changes were found at post-tests.

Table 7.1 Demographic characteristics of family carers in mutual support group, standard care and those not recruited in the main study

Characteristics	Mutual support (n = 38)		Standard care (n = 38)		Total (N = 76)		Eligible but not recruited (n = 124)	
	f	%	f	%	f	%	f	%
Gender								
Male	16	42.1	18	47.4	34	44.7	56	45.2
Female	22	57.9	20	52.6	42	55.3	68	54.8
Age	M=34.9, SD=11.6		M= 36.9, SD= 11.4		M=35.9, SD=11.5		M=37.1 SD=12.9	
20-29	15	39.5	16	42.1	31	40.8	52	41.9
30-39	11	28.9	9	23.7	20	26.3	38	30.6
40-49	4	10.5	6	15.8	10	13.2	14	11.3
50-62	8	21.1	7	18.4	15	19.7	20	16.1
Education level								
Primary school or below	10	26.3	13	34.2	23	30.3	38	30.6
Secondary school	24	63.2	21	55.3	45	59.2	71	57.3
Tertiary [a]	4	10.5	4	10.5	8	10.5	15	12.1
Relationship with patient								
Spouse	16	42.1	14	36.8	30	39.5	48	38.7
Parent	10	26.3	13	34.2	23	30.3	40	32.3
Child	4	10.5	4	10.5	8	10.5	12	9.7
Sibling & others	8	21.1	7	18.5	15	19.7	24	19.3
Monthly household income (HK dollars)[b]	M=11,500, SD= 1,810		M=10,100, SD= 1,750		M=10,800, SD= 1,890		M=11,600, SD= 2,010	
10,000 or below	21	54.3	25	65.8	46	60.5	70	56.4
10,001 – 20,000	12	31.6	10	26.3	22	29.0	36	29.0
20,001 – 30,000	4	10.5	2	5.3	6	7.9	10	8.1
30,001 – 40,000	1	2.6	1	2.6	2	2.6	8	6.5
Number of family members living with patient	M=2.8, SD=0.9		M=2.7, SD=1.2		M=2.8, SD=1.1		M=2.8, SD=1.4	
One	12	31.6	10	26.3	22	29.0	37	29.9
Two	13	34.2	15	39.5	28	36.8	49	39.5
Three to four	12	31.6	10	26.3	22	29.0	34	27.4
Five to six	1	2.6	3	7.9	4	5.2	4	3.2

Note: f = frequency, % = percentage, M = mean, SD = standard deviation.

[a] Tertiary education refers to studies completed in university or other postgraduate programs.

[b] US$1 = 7.8 Hong Kong dollars; UK£ 1 = 14 Hong Kong dollars.

Table 7.2 presents the socio-demographic characteristics of the patients with schizophrenia in the mutual support and standard care groups and of those eligible patients who were not recruited in this study. Similar to the comparisons of family carers' characteristics, there were no statistically significant differences found in these patients' characteristics between the mutual support group, the standard care group and those eligible to be but not recruited families, at this baseline measurement. Female patients (55.3% - 60.5%) were slightly more than male (39.5% - 44.7%) in the three groups. About 90% of them were adolescents or young adults (age range 19-30 years) and their mean age was about 25-26 years. Similar to their family carers, most of them (about 90%) had completed secondary school education and the average duration of the patients' illness was similar between the three groups, about 2.6-2.8 years (SD= 0.7– 0.2). More than half of them had been rated by their family carer as having a stable mental condition in the last three months prior to baseline measurement. Most patients in the three groups were taking conventional antipsychotic medications only (73.7% - 79.0%) such as chlorpromazine and haloperidol, with more than half (57.9% - 63.2%) taking medium doses of these drugs (i.e. between 8 – 10 mg/day in terms of haloperidol equivalent mean values, as recommended by Bezchlibnyk-Butler and Jeffries, 1998). In addition, the dosages of neuroleptic medications used by the patients in the mutual support and control groups did not differ within and between groups over the follow-up period, using Goodness-of-fit Chi-square test ($p< 0.5$ and $p< 0.1$, respectively). There were also no significant differences in the types of medication used by the patients within and between the two groups using Chi-square tests ($p< 0.1$ and $p< 0.2$, respectively).

7.3 CORRELATIONS BETWEEN STUDY VARIABLES AT BASELINE MEASUREMENT

Relationships between all outcome variables in this study were assessed in order to identify any potential covariate effect of the variables on the primary outcome measure - family burden and each of the secondary outcome measures at the baseline measurement, using Pearson's product-moment correlation (for interval data), Spearman's rank correlation (for ordinal data) and point bi-serial correlation (for nominal data) tests. This covariant effect was taken account when examining the composite effect of the interventions and outcome measures used in this study between groups over time (see Section 7.4.3). Results are summarised in Appendix 13. Mean scores of the outcome

Table 7.2 Socio-demographic characteristics of patients in the mutual support and standard care groups and other eligible participants in the OPDs

Characteristics	Mutual support (n = 38)		Standard care (n = 38)		Total (N = 76)		Eligible but not recruited (n = 124)	
	f	%	f	%	f	%	f	%
Gender								
Male	17	44.7	15	39.5	32	42.1	52	41.9
Female	21	55.3	23	60.5	44	57.9	72	58.1
Age	M= 25.3, SD= 7.3		M=25.7, SD= 6.9		M= 25.6, SD= 7.0		M= 26.1, SD= 9.0	
19-24	19	50.0	13	34.2	32	42.1	55	44.4
25-30	15	39.5	22	57.9	37	48.7	58	46.7
31-50	4	10.53	3	7.9	7	9.2	11	8.9
Duration of illness at baseline (years)	M=2.7, SD=1.1		M= 2.6 SD= 0.7		M= 2.7, SD= 0.9		M= 2.8 SD= 1.2	
Less than two	19	50.0	15	39.5	34	44.7	57	46.0
Two to three	13	34.2	12	31.6	25	32.9	38	30.6
Three to five	6	15.8	11	28.9	17	22.4	29	23.4
Education level								
Primary school or below	4	10.5	4	10.5	8	10.5	14	11.3
Secondary school	26	68.4	27	71.1	53	69.7	85	68.5
Tertiary [a]	8	21.1	7	18.4	15	19.8	25	20.2
Patient's mental condition in the past 3 months [b]								
Improved	7	18.4	7	18.4	14	18.4	24	19.4
Staying the same	23	60.5	19	50.0	42	55.3	66	53.2
Worsened/Not stable	8	21.1	12	31.6	20	26.3	34	27.4
Current dosage of antipsychotic medication [c]								
Low	4	10.5	5	13.2	9	11.9	17	13.7
Medium	22	57.9	24	63.1	46	60.5	75	60.5
High	12	31.6	9	23.7	21	27.6	32	25.8

Note: f = frequency, % = percentage, M = mean, SD = standard deviation.

[a] Tertiary level of education refers to studies completed in university and other postgraduate studies in Hong Kong.

[b] Family carers' rating of patients' mental condition during the past three months when compared with the whole year.

[c] Dosage levels of neuroleptic medications were compared with average dosage of medication taken by patients in haloperidol equivalent mean values in mg/day, as recommended by American Psychiatric Association (Bezchlibnyk-Butler & Jeffries, 1998).

measures including the Family Burden Interview Schedule (FBIS), Family Assessment Device (FAD), 6-item Social Support Questionnaire (SSQ6) - number of support persons, SSQ6 - level of satisfaction, Specific Level of Functioning scale (SLOF) were significantly and strongly correlated with each other (Pearson's correlation coefficient

r= 0.44 – 0.87, p< 0.0005). Therefore, these outcome variables were analysed together to examine the composite effect of intervention between groups and over time, using repeated-measures multivariate analysis of variance (MANOVA) and followed by Roy-Bargmann step-down analysis with a series of univariate analysis of covariance tests (see Section 6.10.1 in Chapter 6 for detail description of this data analysis strategy).

Other statistically significant correlations between the study variables included: (a) the mental state of the patients over the last three months was positively correlated with their medication dosage (Spearman's r_s= 0.48, p< 0.0005), the Family Support Services Index (FSSI) - community services that families needed (r_s= 0.25, p< 0.05), and length of patients' re-hospitalisations in days per month (r_s= 0.24, p< 0.05); (b) the duration of illness was positively correlated with the SLOF (r_s= 0.27, p< 0.05); (c) the medication dosage was positively correlated with the length of patients' re-hospitalisation (r_s= 0.26, p< 0.05); (d) the FSSI - community services that families were receiving was positively correlated with the FSSI - community services that families needed (Pearson's r= 0.28, p< 0.05) and average number of family conflicts per month (r= 0.25, p< 0.05); and (e) the amount of family conflicts was negatively correlated with the family burden score (r= -0.34, p< 0.05) and positively correlated with the family functioning score (r= 0.30, p< 0.05). Not surprisingly, these results showed that the patients with a more unstable mental state in the past three months had taken a higher dosage of medication, had experienced a longer length of re-hospitalisation and had made greater demands of community services. The patients (who had taken a higher medication dosage) with a lower level of psychosocial functioning also indicated longer duration of illness. There was also a significant positive correlation between the amount of community services that the families were receiving and the amount that they needed. It is not surprising that the average amount of family conflicts per month, which reflected the family's cohesion and relational problems, was associated with family burden and functioning. However, it is interesting to note that the amount of services that the families were receiving was significantly and positively correlated with their average amount of family conflicts.

7.4 TREATMENT EFFECTS OVER THE 12-MONTH FOLLOW-UP

This section presents the treatment effects of the mutual support group intervention for the families of patients with schizophrenia over the 12-month follow-

up period, when compared with the standard care group. Results of multivariate analyses of the five correlated outcome variables and univariate analyses of the other dependent variables are presented. Comparison of the demographic characteristics and outcome scores between the three mutual support subgroups is summarised in Section 7.4.6. Section 7.4.7 describes the results of the analyses of the clinical significance of the treatment effects of the support group.

7.4.1 Testing the statistical assumptions for multivariate analyses

The power of the multivariate analysis used for these outcome measures was maintained by having equal sample size between the two groups and no missing or incomplete data in this study. Preliminary assumption testing of all study variables was conducted for univariate and multivariate outliers, normality, linearity, homogeneity of variances, and multi-collinearity (Stevens, 1996), with no serious violation noted. A detailed description of the results of the assumption testing was presented in Chapter 6 (Section 6.10.1). All correlations among the five study variables (FBIS, FAD, SSQ6 – number of support persons, SSQ6 – level of satisfaction, and SLOF) were in excess of 0.30 and the homogeneity of regression (i.e. non-significant F values, with all p values > 0.05) and homogeneity of variance-covariance matrices (i.e. non-significant F value with p> 0.01 in the Box's M test) were established for all components of the Roy-Bargmann step-down analysis (Tabnachnick & Fidell, 2001). The log-determinant of the pooled within-cells correlation matrix and its determinant were found to be sufficiently different from zero, indicating no multi-collinearity (Stevens, 2002).

Using a two-tailed independent-samples t-test, the pre-test mean scores revealed no significant differences (p> 0.05) between the mutual support and standard care groups, indicating homogeneity of the subjects of the two groups at the baseline.

7.4.2 Mean scores and standard deviations of the outcome measures at pre-test and post-tests

The mean scores and standard deviations of all outcome measures and their subscales at the baseline measurement and three post-tests are summarised in Table 7.3. As indicated in Table 7.3, the mean scores of the measures at the baseline measurement were similar between the participants in the mutual support and standard care groups. At the pre-test, the mutual support and standard care groups generally

indicated a moderate level of family burden (FBIS, possible range 0–50; M= 21.6, SD= 2.4 and M= 22.2, SD= 2.8, respectively) and level of satisfaction with social support (SSQ6 – level of satisfaction, possible range 0–6; M= 3.1, SD= 0.6 and M= 3.1, SD= 0.6, respectively), and a low level of overall family functioning (FAD, possible range 0–42; M= 16.1, SD= 0.9 and M= 16.2, SD= 1.2, respectively). The patients in the mutual support and standard care groups showed a moderate level of psychosocial functioning (SLOF, possible range 43–215; M= 148.3, SD= 8.8 and M= 147.0, SD= 8.3, respectively) and low severity of psychiatric symptoms (BPRS, possible range 0–108; M= 25.7, SD= 2.2 and M= 25.6, SD= 2.7, respectively).

In addition, as shown in Table 7.3, the mutual support group indicated consistent positive improvements in the mean scores of most of the family and patient measures including the FBIS, FAD and its subscales, FSSI – family support service received, SSQ6 - number of support persons, SSQ6 - level of satisfaction, SLOF and its subscales, length of patients' re-hospitalisation, and average amount of family conflicts per month, from the pre-test to post-test 3 (12 months following closure of intervention); whereas the standard care group showed consistent slight or marked negative changes in the mean scores of these outcomes. The average amount of community services that the families needed gradually reduced from 6.8 to 4.8 in the mutual support group but slightly increased from 6.3 to 7.7 at the first post-test and 6.6 at the third post-test. However, the mutual support and standard care group had similar slight and irregular changes in the mean scores of the BPRS at the pre-test and three post-tests (M= 24.8–26.0 and SD= 1.8–2.7 in the two groups).

The estimated marginal means, standard errors and 95% confidence intervals of the five correlated measures (FBIS, FAD, SSQ6 – number of support persons, SSQ6–level of satisfaction, SLOF) and other secondary outcome measures at the baseline measurement and three post-tests for the analyses of variance testing are attached in Appendix 14. The estimated marginal means of the outcome measures at pre-test and post-tests, which indicated their adjusted mean scores used in the analyses of variance to compare any significant differences on the outcomes between and within the two study groups at the pre-test and three post-tests, were very similar to the initial mean scores of the measures. This indicated that only very mild adjustments of these mean scores at the pre-test and post-tests were due to covariant effect of the measures over time.

Table 7.3 Means and standard deviations of outcome measures at baseline and post-tests

Measures (possible score range)		Baseline		Post-test 1		Post-test 2		Post-test 3	
		M	SD	M	SD	M	SD	M	SD
FBIS (0-50)	MS	21.6	2.4	18.7	3.6	17.1	3.6	15.9	3.1
	SC	22.2	2.8	25.7	3.4	24.3	3.6	25.5	3.0
Finance	MS	4.3	0.6	3.9	0.7	3.6	0.5	3.3	0.7
	SC	4.5	0.7	5.2	1.0	4.9	1.0	5.0	0.9
Family activities	MS	7.1	0.6	6.0	0.9	5.7	0.9	5.2	0.8
	SC	7.3	0.7	8.4	1.0	8.0	1.1	8.4	1.1
Interactions	MS	4.0	0.9	3.3	0.7	3.0	0.7	2.7	0.6
	SC	4.2	0.8	4.9	0.9	4.6	1.0	4.9	1.0
Physical health	MS	3.0	0.5	2.8	0.7	2.8	0.7	2.7	0.8
	SC	3.0	0.5	3.4	0.9	3.2	0.9	3.2	0.9
Mental health	MS	3.1	0.5	2.6	0.5	2.0	0.6	2.0	0.7
	SC	3.3	0.6	3.9	0.8	3.7	0.8	4.0	0.9
FAD (7-28)	MS	16.1	0.9	17.7	1.0	20.2	1.4	21.3	1.2
	SC	16.2	1.2	15.5	1.2	14.5	1.3	14.1	1.0
Problem solving	MS	2.2	0.2	2.3	0.3	2.8	0.3	3.0	0.3
	SC	2.2	0.2	1.9	0.3	1.8	0.3	1.8	0.3
Communication	MS	2.3	0.2	2.5	0.3	2.8	0.3	3.0	0.2
	SC	2.3	0.3	2.1	0.2	2.0	0.2	2.0	0.1
Role performance	MS	2.3	0.2	2.5	0.2	2.8	0.2	3.0	0.2
	SC	2.3	0.2	2.1	0.2	2.0	0.2	2.0	0.2
Affect responsiveness	MS	2.4	0.3	2.7	0.4	3.0	0.3	3.2	0.2
	SC	2.4	0.3	2.4	0.3	2.3	0.3	2.2	0.2
Affect involvement	MS	2.4	0.2	2.7	0.3	3.0	0.3	3.2	0.3
	SC	2.4	0.3	2.4	0.3	2.3	0.2	2.2	0.2
Behaviour control	MS	2.2	0.2	2.4	0.3	2.8	0.2	3.0	0.2
	SC	2.3	0.2	2.2	0.3	2.0	0.2	2.0	0.1
General functioning	MS	2.4	0.2	2.6	0.3	2.9	0.3	3.0	0.3
	SC	2.3	0.2	2.3	0.3	2.1	0.2	2.0	0.2
FSSI									
Services in need (0-16)	MS	6.8	1.4	6.1	0.9	5.0	0.6	4.8	1.0
	SC	6.3	1.9	7.7	1.5	7.5	1.2	6.6	1.1
*Services receiv*ing *(0-16)*	MS	4.3	1.3	4.5	1.2	4.5	0.7	4.4	1.0
	SC	4.0	1.2	5.2	1.1	5.0	0.9	4.0	0.8
SSQ6									
No. of support persons (0-9)	MS	3.0	0.7	3.3	0.6	3.8	0.5	4.3	0.7
	SC	3.0	0.7	2.8	0.6	2.6	0.7	2.5	0.5
Level of satisfaction (0-6)	MS	3.1	0.6	3.3	0.6	3.7	0.6	4.2	0.7
	SC	3.1	0.6	2.7	0.6	2.3	0.7	2.3	0.5
SLOF - Total score (43-215)	MS	148.3	8.8	161.6	9.6	170.0	6.7	174.6	6.5
	SC	147.0	8.3	145.0	11.0	137.3	10.5	133.6	9.9
Physical function	MS	21.4	1.4	22.6	1.5	22.9	1.1	23.3	0.9
	SC	21.8	1.3	22.1	1.6	21.8	1.9	21.0	1.4
Personal care	MS	26.2	2.4	29.6	3.0	30.4	2.5	31.1	2.5
	SC	25.5	2.5	26.3	2.7	24.5	2.4	23.7	2.3
Interpersonal relationship	MS	22.8	3.6	24.1	4.7	26.3	3.2	27.2	2.9
	SC	24.3	2.5	22.5	3.6	20.7	2.5	20.3	2.3
Social acceptability	MS	25.6	2.6	27.0	2.1	28.3	2.1	29.0	2.1
	SC	25.3	2.5	23.3	3.4	21.9	2.9	21.2	2.6

Activities of daily living	MS	30.7	3.7	36.2	3.9	37.2	3.0	37.7	2.8
	SC	28.1	3.2	30.8	4.7	27.3	4.1	26.6	4.1
Work skills	MS	21.6	2.0	22.2	3.3	24.8	2.2	26.1	1.9
	SC	22.0	1.6	20.0	2.3	21.0	3.2	20.8	2.8
Re-hospitalisation (days/month)	MS	8.1	6.0	6.4	3.4	5.6	4.4	4.5	3.9
	SC	8.6	6.1	9.6	6.2	11.3	6.7	12.6	7.8
Number of family conflicts per month	MS	6.5	2.2	6.1	1.7	4.9	1.3	4.2	1.4
	SC	6.2	1.8	6.5	1.6	7.7	1.5	7.9	1.4
BPRS (0-108)	MS	25.7	2.2	26.0	2.1	24.8	1.8	24.9	2.1
	SC	25.6	2.7	26.0	2.2	25.5	1.8	25.6	2.1

Note: MS: Mutual support group; SC: Standard care. BPRS: Brief Psychiatric Rating Scale; FBIS: Family Burden Interview Schedule; FAD: Family Assessment Device; FSSI: Family Support Service Index; SLOF: Specific Level of Functioning scale; SSQ6: 6-item Social Support Questionnaire.

7.4.3 Treatment effects on five correlated outcome measures

As described in the data analysis strategy used for the five statistically correlated outcome measures (FBIS, FAD, SSQ6 – number of support person, SSQ6 – level of satisfaction, and SLOF) in Section 6.10.1 of Chapter 6, the repeated-measures MANOVA test was performed on these five variables. Independent variables were group (mutual support and standard care) and time (baseline and one week, six months and 12 months after intervention). With the use of Wilks' criterion, there was a statistically significant difference between the two groups in the combined dependent variables, $F(5, 70)= 65.20$, $p< 0.0005$; Wilks' Lambda= 0.18, multivariate eta squared= 0.82 (large effect; Cohen, 1988), between time points, $F(15, 60)= 18.55$, $p< 0.0005$, Wilks' Lambda= 0.18, multivariate eta squared= 0.82 (large effect), and their interaction, $F(15, 60)= 84.61$, $p< 0.0005$, Wilks' Lambda= 0.05, and the multivariate eta squared was 0.95 (large effect). These multivariate analysis results are summarised in Appendix 10, for group and time effects and group by time interaction.

With significant main effects in MANOVA, the univarate analyses of variance and step-down analysis of the five prioritised outcome variables were performed and the SPSS outputs are also presented in Appendix 10. An experiment-wise error rate of 1% was achieved by the apportionment of alpha as shown in the last column of the third part for each of the variables. According to the entry priority for step-down analysis, unique contributions to predicting differences between the two groups were made by: (a) the highest priority dependent variable FBIS, step-down $F(1, 74)= 25.66$, $p< 0.0005$ and partial eta squared= 0.24; (b) the FAD, step-down $F(1, 73)= 37.79$, $p< 0.0005$ and partial eta squared= 0.22; (c) the SLOF, step-down $F(1, 72)= 123.20$, $p< 0.0005$ and partial eta squared= 0.50; and (d) SSQ6 - number of support persons, step-

down F (1, 71)= 3.98, p< 0.01 and partial eta squared= 0.04. Although a univariate comparison revealed that satisfaction of social support (SSQ6 – level of satisfaction) in the mutual support group was significantly higher than that of the standard care group, F (1, 74)= 97.79 and p< 0.0005, this difference was already represented in the step-down analysis by higher priority dependent variables.

These four variables (FBIS, FAD, SLOF, and SSQ6 - number of support persons) also made unique contributions to the composite effect in terms of time. The greatest contribution was made by the FAD, step-down F (3, 221) = 44.40, p < 0.0005 and partial eta squared = 0.19, with differences due to the FBIS and SLOF already entered. Unique contributions of between-group effect over time were also made by: (a) the SLOF, step-down F (3, 220) = 15.89, p < 0.0005 and partial eta squared = 0.08; (b) the FBIS, step-down F (3, 222) = 9.19, p < 0.0005 and partial eta squared = 0.07; and (c) the SSQ - number of support persons, step-down F (3, 219) = 4.57, p < 0.004 and partial eta squared = 0.05. However, there were no statistical differences of satisfaction of social support (SSQ6 - level of satisfaction) between the mutual support and standard care groups over time. As the FBIS was scored reversely, thus the mutual support group showed lower family burden (mean FBIS = 17.86, SE = 0.80) than the standard care group (mean FBIS = 24.01, SE = 0.68) over the six-month intervention and 12-month follow-up period. After adjustment by the higher priority dependent variables, the patient functioning (adjusted mean SLOF = 165.03, SE = 1.58), family functioning (adjusted mean FAD = 18.98, SE = 0.19) and number of support persons (adjusted mean SSQ6 - number of support persons = 3.50, SE = 0.24) in the mutual support group were significantly higher than those of the standard care group (adjusted mean SLOF = 142.14, SE = 1.12; adjusted mean FAD = 15.16, SE = 0.15; adjusted mean SSQ6 - number of support persons = 2.80, SE = 0.12), over the follow-up period.

Similarly, for the group by time interaction, the mutual support group indicated significant improvements on: (a) the FBIS, step-down F (3, 222) = 54.45, p < 0.0005, partial eta squared = 0.17; with differences due to the higher priority variables, (b) the FAD, step-down F (3, 221) = 75.95, p < 0.0005 and partial eta squared = 0.32; (c) the SLOF, step-down F (3, 220) = 74.79, p < 0.0005 and partial eta squared = 0.21; and (d) the SSQ6 - number of support persons, step-down F (3, 219) = 3.78, p < 0.01 and partial eta squared = 0.06. The univariate analysis of group by time effect of the SSQ6 – level of satisfaction showed that the mutual support group indicated significantly higher satisfaction level of social support than that of the standard care group over

time, F (1, 74) = 96.97, however, the difference was already accounted for in the composite effect by the higher priority dependent variables (i.e. FBIS, FAD, SLOF, and SSQ - number of support persons).

7.4.4 Treatment effects on other outcome measures using univariate analyses

The repeated measures between-within subjects ANOVA (group x time) was conducted to compare the effects of the intervention between groups over time and the group by time interaction on the other outcome variables (i.e. FSSI, length of patients' re-hospitalisation, average amount of family conflicts, and BPRS). The estimated marginal means, standard errors and 95% confidence intervals of these variables at baseline and three post-tests are presented in Appendix 14. Results of the repeated-measures two-way ANOVA are summarised in Table 7.4. With consideration to multiple testing, Bonferroni's corrected p value of 0.01 (i.e. 0.05 divided by 5) was used. From the Wilks' Lambda in the multivariate tests (i.e. the most commonly reported statistic, even though all of the multivariate tests yielded the same results in this study), there were statistically significant changes in the amount of community services that the families needed and that they were receiving (p values = 0.0005), and length of patients' re-hospitalisation in days per month (p = 0.008), across the three post-test periods (i.e. one week, six months and 12 months after intervention). The effect sizes of these changes over time were large (eta squared= 0.47, 0.30 and 0.18, respectively, as recommended by Cohen in 1992).

Table 7.4 Results of repeated-measures ANOVA for the FSSI, length of re-hospitalisation, family conflicts, and BPRS

Measures	Between-group		Within-group (time effect)		Interaction effect (group x time)
	F (1, 74), p	Eta Squared	Wilks' Lambda, p	Eta Squared	Wilks' Lambda, p
FSSI					
Services in need	40.69, p= 0.0005	0.36	0.527, p= 0.0005	0.47	0.50, p= 0.0005
Services receiving	0.39, p= 0.532	0.01	0.699, p= 0.0005	0.30	0.71, p= 0.02
Re-hospitalisation (days/month)	44.68, p= 0.0005	0.38	0.764, p= 0.008	0.18	0.77, p = 0.0005
Amount of family conflicts per month	27.65, p= 0.0005	0.27	0.940, p= 0.215	0.06	0.33, p= 0.0005
BPRS	0.74, p= 0.392	0.01	0.876, p= 0.022	0.12	0.98, p= 0.63

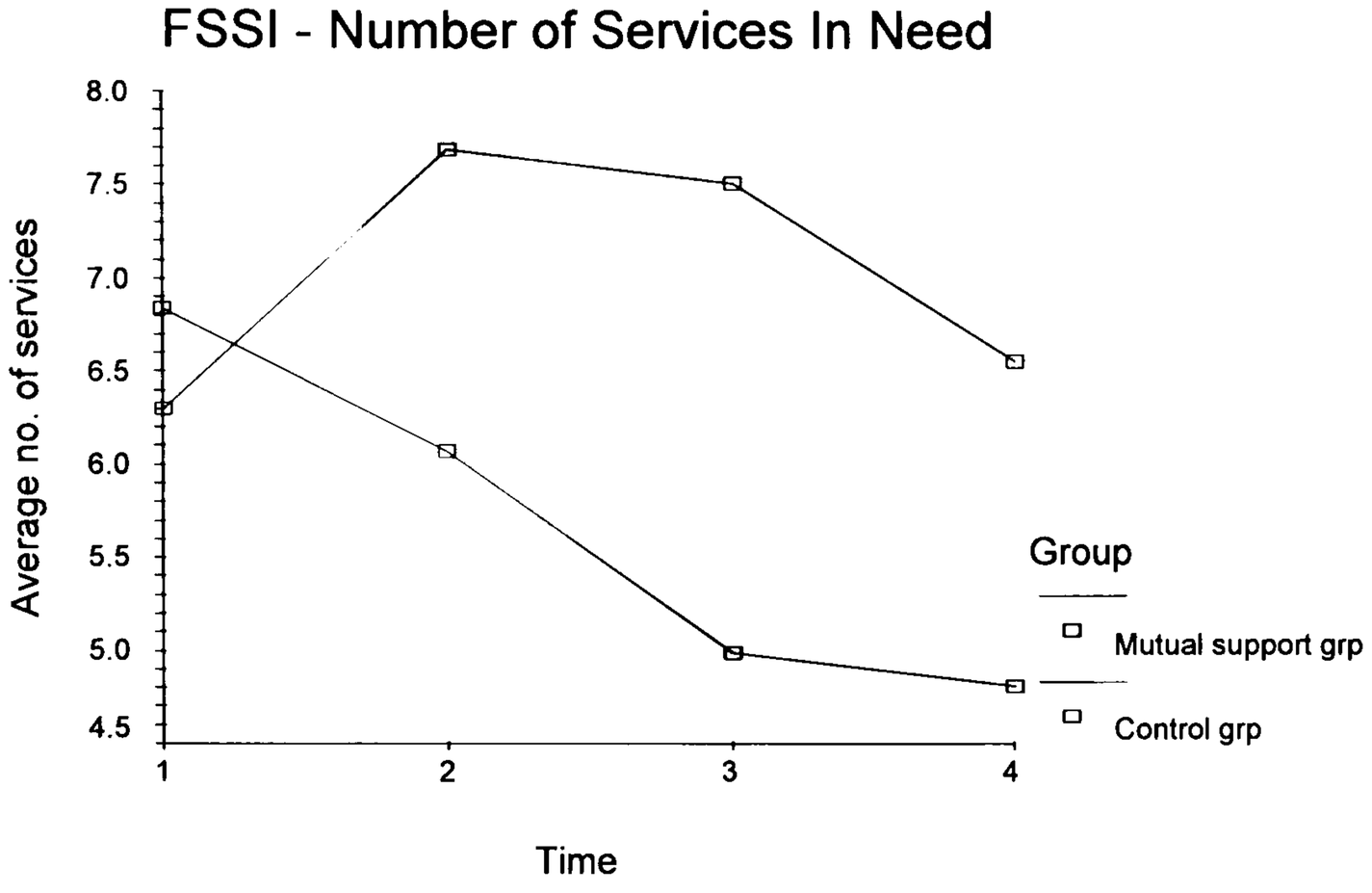
Note: BPRS: Brief Psychiatric Rating Scale; FSSI: Family Support Services Index.
The significance levels of the ANOVA tests were set at 0.01, using Bonferroni's correction.

For the between-group effect, the mutual support group reported a statistically significant reduction of the amount of family support services needed, patient re-hospitalisation in days per month and average number of family conflicts (all p values = 0.0005), when compared with the standard care group, and all the effect sizes were large (eta squared= 0.27 – 0.38). In addition, the group by time interaction effects of the community services that the families needed, length of patients' re-hospitalisation and average amount of family conflicts were significant (p= 0.0005). These results showed that the mutual support group reported a significantly greater reduction of family services needed and length of patients' re-hospitalisation over the 18-month study period (p values = 0.0005), than the participants under standard care. For the average amount of family conflicts, the group by time interaction effect was also significant, even though the within-group time effect was non-significant. This suggests that the two groups did not have any significant change in the average amount of family conflicts across the three post-test periods, however, the support group showed a consistent mild reduction of family conflicts (from M= 6.5 at baseline to M= 4.2 at post-test 3) while the standard care group reported a consistent slight increase of this (from M= 6.2 at baseline to M= 7.9 at post-test 3).

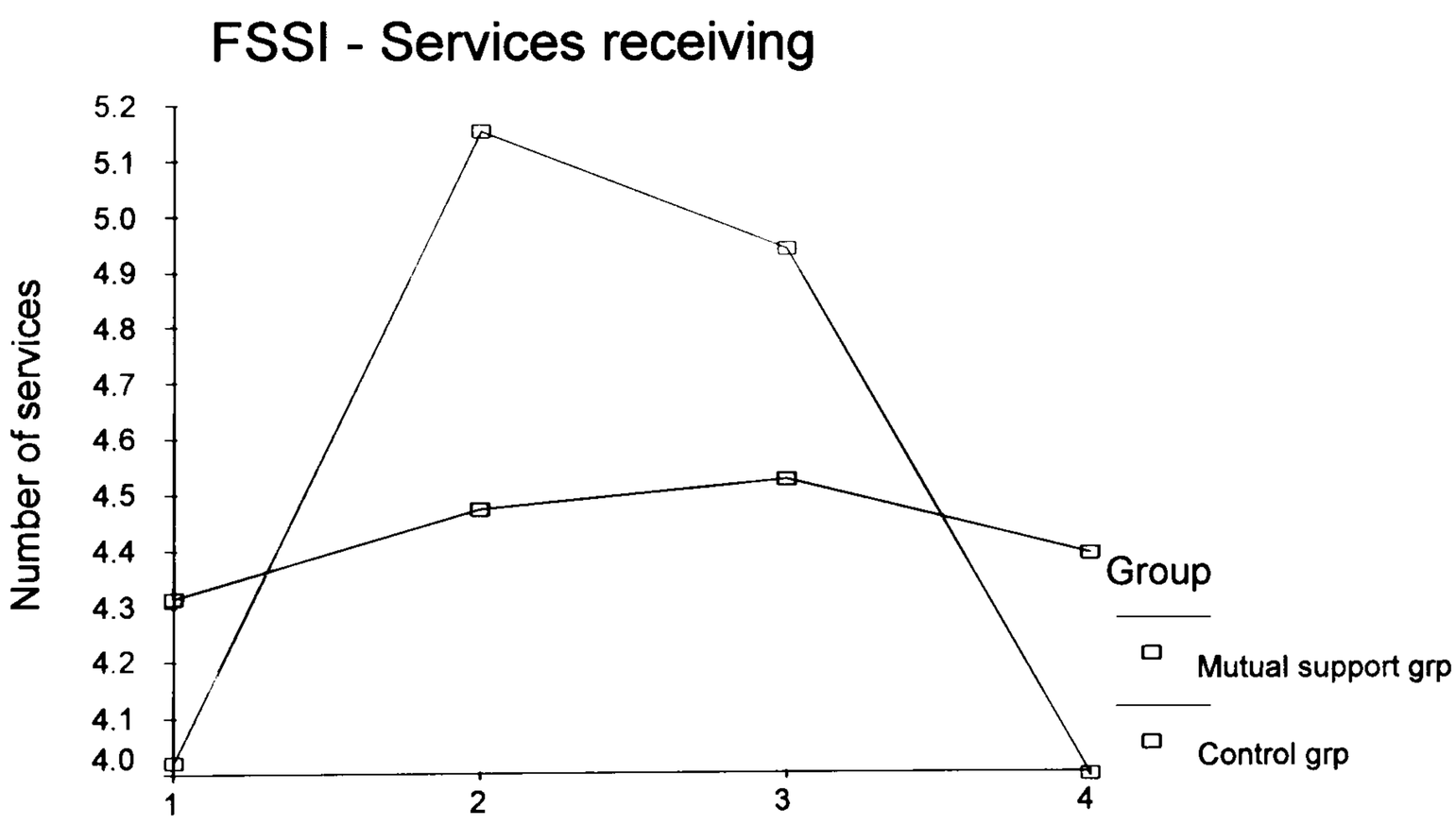
Otherwise, there were no significant differences in symptom severity of the patients using the BPRS and the community services that the families were receiving between the two groups across the 18-month study period. The profile plots of the FSSI - amount of community services that families needed, FSSI – amount of services families were receiving, length of patients' re-hospitalisation, amount of family conflicts, and BPRS scores over the study period using the estimated marginal means, are presented in Figure 7.1. The figures showed a regular reduction of the amount of services (FSSI) that the families needed, length of patients' hospitalisation and average amount of family conflicts in the mutual support group, whereas the standard care group indicated a gradual increase of the scores in these three measures. However, there are irregular changes in the amount of services that the families were receiving and the BPRS scores in the two study groups. In the mutual support group, the families indicated a marked increase of service utilisation at the first post-test and their service utilisation gradually decreased at the second and third post-tests; and the standard care group only showed slight changes in the service utilisation at all post-tests. In the two groups, the patients' symptom severity (BPRS score) slightly increased at post-test 1, reduced at post-test 2 and remained constant at post-test 3.

Figure 7.1 Profile plots of the FSSI, length of re-hospitalisation, family conflicts, and BPRS over the study period

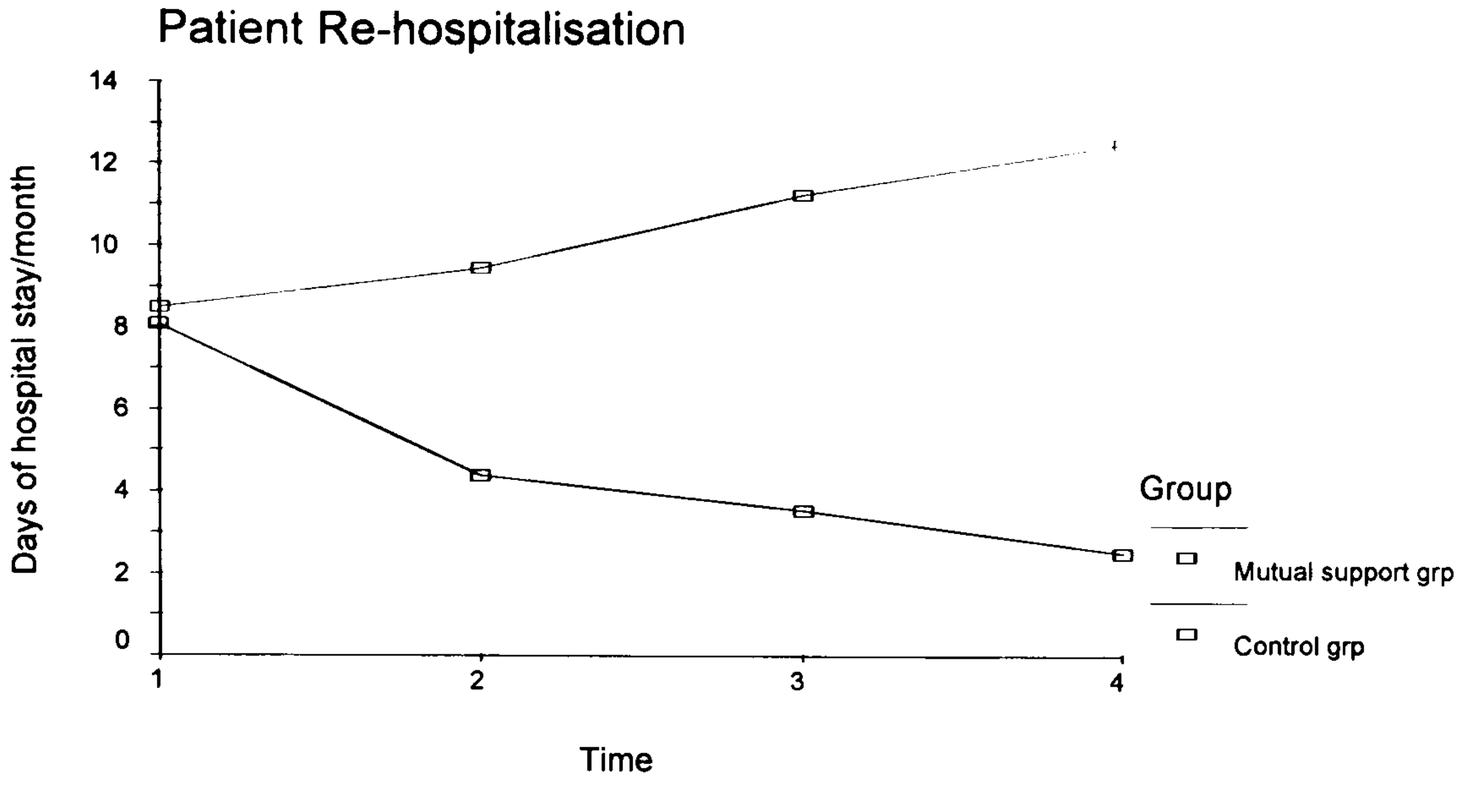
(a) Profile of FSSI – amount of services families needed



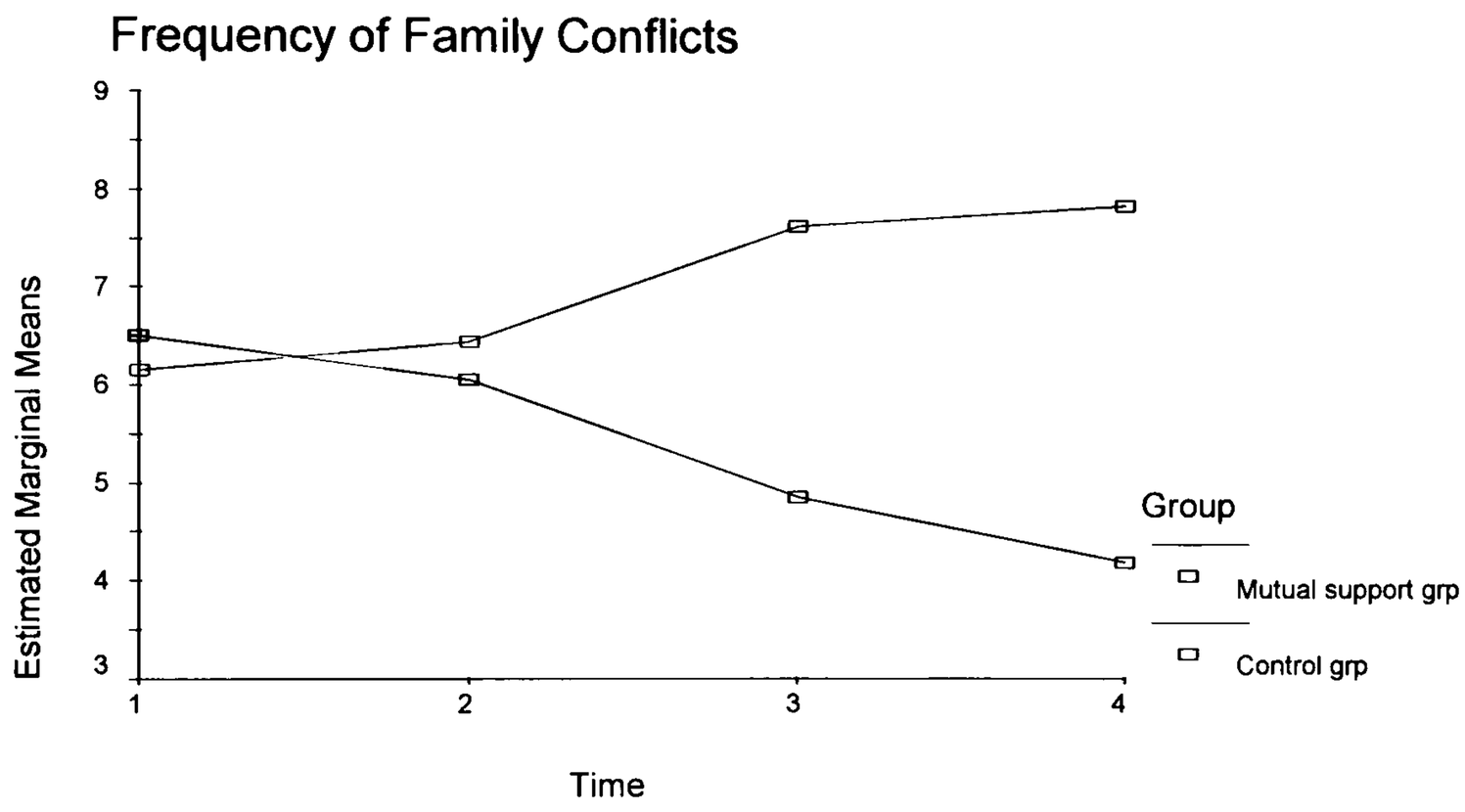
(b) Profile of FSSI – amount of services families were receiving



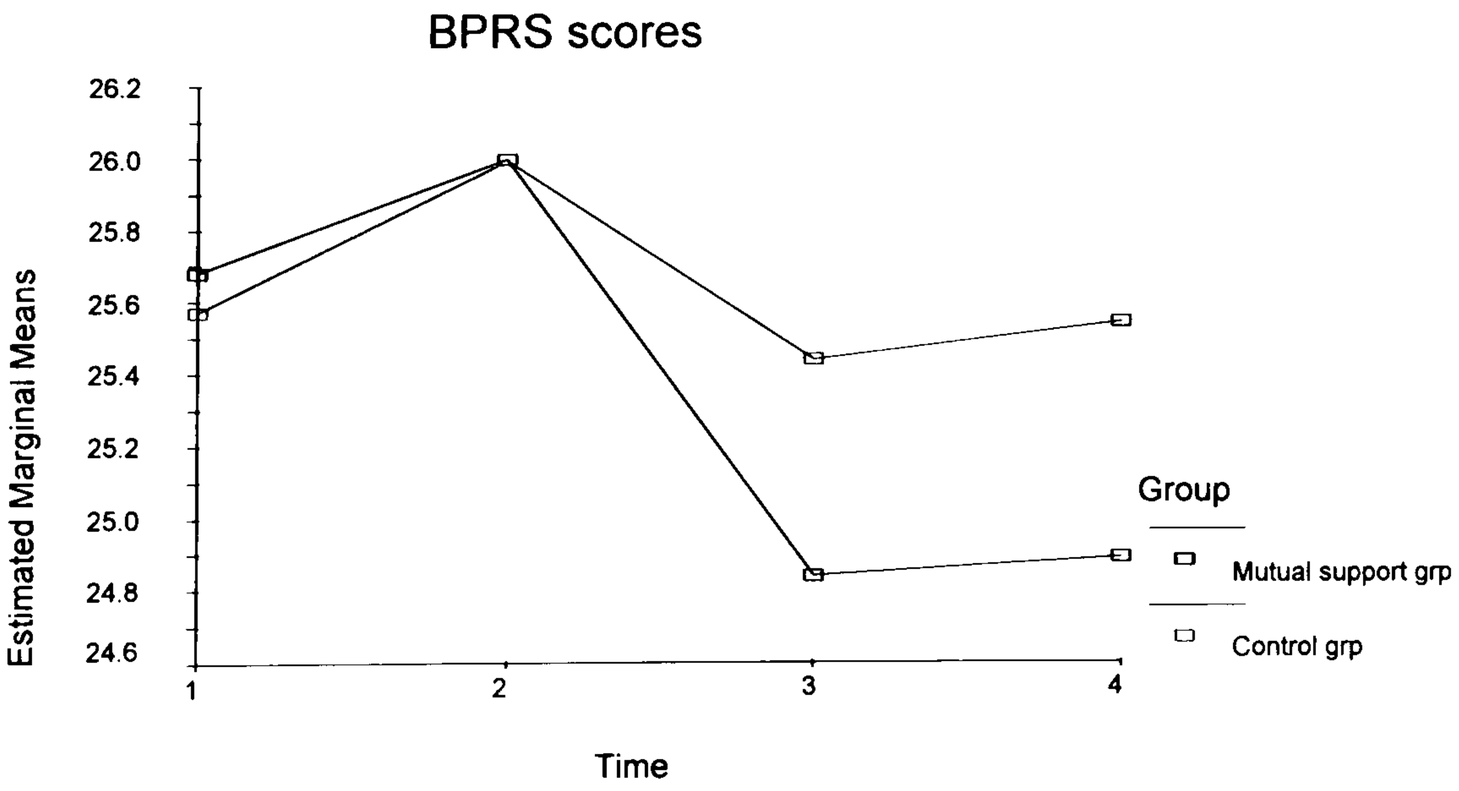
(c) Profile of length of patients' re-hospitalisation



(d) Profile of average amount of family conflicts



(e) Profile of patients' BPRS scores



Note: Time 1: baseline measurement at recruitment; Times 2, 3 & 4: 1st, 2nd & 3rd post-tests at one week, six months and 12 months after intervention respectively.

7.4.5 Post-hoc comparisons of mean differences between two study groups

Post-hoc comparisons using the Scheffe's comparison test evaluated the pairwise mean differences of each outcome variable, which indicated statistically significant difference between the two study groups over time in the multivariate or univariate analyses of variance. The comparison results for the FBIS, SSQ6 - number of support persons, SLOF, FAD, length of patients' re-hospitalisation, FSSI - amount of community services that families needed, and average amount of family conflicts are summarised in Table 7.5.

The results in Table 7.5 indicated that the mean scores of the FBIS, FAD, SLOF, SSQ6 - number of support persons, length of patients' re-hospitalisation, and FSSI – amount of community services that families needed for the three post-tests of the mutual support group, were statistically significantly different from the standard care group (all p values = 0.0005, except p= 0.05 for SSQ6 - number of support persons at the post-test 1). The results also indicated significant differences in the average number of family conflicts at the post-tests 2 and 3 between the two groups (p values = 0.0005). Therefore, the mutual support group reported relatively more significant improvements in these psychosocial outcomes than standard care.

In addition, post-hoc Scheffe's comparisons were also performed on the five subscales of the FBIS. The results indicated highly significant differences in the mean scores of the four subscales of the FBIS between the two groups in the three post-tests, including financial burden, family activities (routine and leisure), interactions, and mental health (all p values > 0.0005). The results meant that the mutual support group reported much greater improvement in the four aspects of family burden, when compared with the controls. However, there was no significant difference in the mean score of the 'physical health' subscale (p= 0.08).

7.4.6 Comparison of demographic characteristics and outcome scores between three mutual support subgroups

The demographic characteristics of the three mutual support subgroups are summarised in Appendix 14. There were no statistically significant differences in any of these characteristics between the three subgroups (p > 0.1), using Chi-square test (e.g. gender), Kruskal-Wallis test (e.g. perceived mental state) or ANOVA (e.g. age).

Table 7.5 Results of Scheffé's pairwise comparisons of outcome scores indicated significant effect between groups over time

	Post-test 1			Post-test 2			Post-test 3		
Measures	MD	SE	95% CI	MD	SE	95% CI	MD	SE	95% CI
FBIS	7.1**	1.2	4.7-9.3	7.2**	1.3	4.7-9.8	9.6**	1.2	7.3-11.9
FAD	2.3**	0.3	1.8-2.8	5.7**	0.3	5.1-6.3	7.2**	0.3	6.7-7.7
SLOF	16.6**	2.4	11.9-21.3	32.7**	2.0	28.7-36.7	40.9**	1.9	37.1-44.8
SSQ6- no. of support persons	0.4*	0.1	0.2-0.7	1.2**	0.2	0.9-1.5	1.8**	0.2	1.5-2.1
Rehospitali-sation	5.1**	1.2	2.7-7.6	7.7**	1.4	5.0-10.5	10.0**	1.4	7.2-12.9
FSSI - services in need	1.6**	0.3	1.1-2.2	2.5**	0.2	2.1-2.9	1.8**	0.2	1.3-2.2
No. of family conflicts	0.4	0.4	0.4-1.2	2.8**	0.3	2.2-3.4	3.7**	0.3	3.0-4.3

Note: MD: Mean difference; SE: Standard error; 95% CI: 95% confidence level for MD.
FBIS: Family Burden Interview Schedule; FAD: Family Assessment Device; FSSI: Family Support Service Index; SLOF: Specific Level of Functioning scale; SSQ6: Six-item Social Support Questionnaire.
* $p < 0.05$, ** $p < 0.0005$

The mean scores and standard deviations of all outcome measures (FBIS, FAD, FSSI, SSQ6, SLOF, length of re-hospitalisation, amount of family conflicts, and BPRS) used in this study for the three mutual support subgroups are also presented in Appendix 14. All of these mean scores were very similar between the three subgroups at the baseline and three post-tests and they followed similar patterns of changes when compared with the whole mutual support group. In addition, the results of repeated-measures ANOVA test for comparisons of these outcome measures between the three subgroups indicated that there were no significant differences between the subgroups at the baseline measurement and three post-tests (all p values > 0.05).

7.4.7 Clinically significant changes in outcome measure scores in the mutual support group

The changes of scores in FBIS, SLOF, FAD, and SSQ6- number of support persons, which showed statistically significant changes in the mutual support group over the 18-month study period, were examined in terms of group and individual levels, using Jacobson and Traux's (1991) criteria of cut-off point for clinically significant change (i.e. at least two standard deviations above the mean score at

baseline, in the direction of functionality). Table 7.6 presents the least changes of the scores considered to be clinically significant and meaningful for the psychosocial measures, the Reliable Change Index (RCI) (representing that the mean difference between two scores is considered to be significant at $p< 0.05$ if it exceeds 1.9) and the number and percentage of the mutual support group participants indicated such significant changes at the three post-tests.

For the mutual support group, clinically significant changes from baseline were found in the FAD (mean difference= 4.1, RCI= 4.1) and SLOF (mean difference= 21.7, RCI= 2.1) at post-test 2; and in FBIS (mean difference= 5.7, RCI= 2.2), FAD (mean difference= 5.2, RCI= 3.5) and SLOF (mean difference= 26.3, RCI= 3.1) at post-test 3.

Table 7.6 Clinically significant changes in scores of the FBIS, SLOF, FAD, and SSQ6- number of support persons for the support group

Measure	CSC [a]	Mutual support (n = 38)		
		Post-test 1 [b]	Post-test 2 [b]	Post-test 3 [b]
FBIS	5.2	3.0 RCI [c] = 1.1	4.5 RCI = 1.6	5.7 [#] RCI = 2.2
FAD	2.0	1.7 RCI = 1.0	4.1 [#] RCI = 2.3	5.2 [#] RCI = 3.5
SLOF	17.1	13.4 RCI = 0.9	21.7 [#] RCI = 2.1	26.3 [#] RCI = 3.1
SSQ6- no. of support persons	1.3	0.3 RCI = 0.6	0.8 RCI = 1.0	1.3 RCI = 1.5

		Post-test 1			Post-test 2			Post-test 3		
		IMP	STA	WOR	IMP	STA	WOR	IMP	STA	WOR
FBIS	n	6	28	4	18	17	3	25	11	2
	%	15.8	73.7	10.5	47.4	44.7	7.9	65.8	29.0	5.3
FAD	n	9	24	5	22	14	2	30	5	3
	%	23.7	63.2	13.2	57.9	36.9	5.3	79.0	13.2	7.9
SLOF	n	5	25	8	10	22	6	20	13	5
	%	13.2	65.8	21.1	26.3	57.9	15.8	52.6	34.2	13.2
SSQ6- no. of support persons	n	4	24	10	8	20	10	12	15	11
	%	10.5	63.2	26.3	21.1	52.6	26.3	31.6	39.5	29.0

[a] Clinical significant difference (CSC): the minimum amount of change in score considered to be clinically significant and is calculated with 2 x standard deviation of the measure in the sample at baseline, in the direction of functionality.
[b] Mean score difference between each post-test and the baseline measurement.
[c] Reliable Change Index shows that mean difference between two scores is considered to be significant at $p < 0.05$, if it exceeds 1.96.
[#] A clinical significant change of the outcome mean score.
IMP: those who indicated clinically significant changes in functional state or became normal in functioning; STA: those who improved but the improvement was not significant; WOR: those who remained unchanged or deteriorated in condition.

When examining the change of scores at individual participant level of the support group, clinically significant changes of the functional state mainly occurred at post-test 3 in the FBIS, FAD and SLOF, in which more than 50% of the participants indicated clinically significant changes in functional states or became normal in these psychosocial functions (65.8%, 79.0% & 52.6%, respectively). However, it is interesting and important to note that 10.5% to 21.1% of the group participants at post-test 1 (one week after intervention), 5.3% to 15.8% at post-test 2 and 5.3% - 13.2% at post-test 3 reported unchanged or deteriorated states of these psychosocial functions. Finally, the number of support persons in the mutual support group did not show any clinically significant increase at all three post-tests and more than one-quarter of them (26.3% at post-tests 1 & 2 and 29.0% at post-test 3) indicated unchanged or a decrease in the number of support persons.

7.5 SUMMARY OF THE RESULTS

A total of 76 families were randomly selected from the list of eligible participants and randomly assigned to either the mutual support group or the control group (i.e. 38 subjects in each group). Average attendance of the mutual support group sessions by the participants was high (M = 9.0, SD = 1.1) and only four family carers in the mutual support group failed to attend a minimum of seven group sessions. One participant in the standard care group was lost to the study after the second post-test, however, the data from all 76 participants, including data from this participant, were used in the final data analysis.

There was significant overall improvement in the psychosocial condition of the family carers and their patients in the mutual support group over the 12-month follow-up period. With the repeated-measures MANOVA and subsequent Roy-Bargmann step-down analysis for the five highly correlated psychosocial measures, the mutual support group indicated statistically significant improvements in family burden and functioning, average number of supporting persons, and patient functioning over the 12 months after intervention, when compared with the standard care group. Of the four effects, however, the effects in family burden and functioning and patient functioning were moderate to large, whereas the increase of the number of support persons showed only a significant but small effect size over the follow-up period.

The results of repeated-measures ANOVA for other psychosocial measures showed that the mutual support group reported a significantly greater reduction of

need for family services and length of patients' re-hospitalisation over the 18-month study period, than the participants under standard care. Also, the mutual support group showed a continuous although limited reduction of family conflicts over time, whilst the standard care group reported a consistent slight increase of this at the three post-tests. Therefore, a significant group by time effect was found in this measure for the mutual support group.

Post-hoc comparisons using the Scheffe's comparison test indicated that the mean scores of the FBIS and other secondary outcomes in the support group including the FAD, SLOF, SSQ6 - number of support persons, patients' re-hospitalisation, and FSSI – amount of community services that families needed at the three post-tests were significantly different from those of the standard care group. There was also significant reduction of the amount of family conflicts at post-tests 2 and 3 in the mutual support group, when compared with the standard care group. In the subgroups analysis, the demographic characteristics and the mean scores of all outcome measures did not show any statistically significant differences between the three mutual support subgroups.

For the mutual support group, clinically significant changes were found in FAD and SLOF at the post-test 2 (six months after intervention), and in the FBIS, FAD and SLOF at the post-test 3 (12 months after intervention).

For the individual participants of the mutual support group, clinically significant changes of their functional state occurred mainly at post-test 2 (6 months after intervention) in FAD and SLOF, and at post-test 3 (12 months following closure of intervention) in the FBIS, FAD and SLOF, in which more than half or two-thirds of the participants indicated a clinically significant improvement in functional state. However, it is noteworthy that about 10 - 20% of the participants at post-test 1, 5 -16% at post-test 2, and also 5-13% at post-test 3 reported unchanged or deteriorated psychosocial functioning. More than one-quarter (26 – 28%) of the mutual support group participants indicated no change or a reduction of the number of support persons at three post-tests.

CHAPTER 8 THERAPEUTIC MECHANISMS OF THE MUTUAL SUPPORT GROUP

8.1 INTRODUCTION

This Chapter presents the results of analyses of the data collected to identify the therapeutic mechanisms of the mutual support group intervention, as perceived by the participants themselves. The findings in this chapter may reveal possible explanations of the effectiveness of the mutual support group tested in this thesis and, thus, the statistical results of the study presented in Chapter 7.

The demographic characteristics of the interviewees are summarised in Section 8.2. Section 8.3 presents the results of the analysis of the interview and group session data, in which the group participants gave their accounts of the psychological and behavioural changes in terms of the five phases of group development suggested by Wheelan (1994) and Kimberly (1997). Section 8.4 describes the themes, which were the factors perceived by the participants as influencing the therapeutic values of the mutual support group. The main themes in relation to the perceived benefits and therapeutic mechanisms of the mutual support group are illustrated with verbatim data. Further extracts from the interviews are presented in Appendix 16 and illustrate the themes and sub-themes from which the therapeutic mechanisms of the mutual support group were derived. Finally, Section 8.5 presents four therapeutic mechanisms of the mutual support group and their potential outcomes by bringing together the findings presented in this chapter and those of the RCT in Chapter 7.

8.2 CHARACTERISTICS OF INTERVIEWEES

Twenty out of the 38 family carers (i.e. 52.6% of total number of the support group participants) were interviewed by the researcher using the interview agenda (see Appendix 9). The other 18 group participants refused to be interviewed, giving as their main reasons: lack of time due to work or being unable to find anyone to take care of their patient; lack of interest, or a feeling that talking about their families and their experiences in the group would be of limited value; while those who had exhibited deterioration in their psychosocial outcomes, felt too embarrassed or guilty about family caregiving to discuss family events or their patient's condition with anyone else. Therefore, 10 participants were interviewed, from those who had shown clinically significant improvements in their psychosocial outcomes (mainly, family burden and

functioning) following the intervention, five from those who had indicated only mild or no change in the study outcomes, and five from those who, according to the outcomes, had shown deterioration or negative changes. Four of them received a second 15-minute interview for clarification and validation of a few important issues identified in the transcription or initial coding of the interview scripts. A sample script of an interview with one carer, who had shown significant improvements after the group intervention, is attached in Appendix 17 for reference.

The major socio-demographic characteristics of the 20 family carers (and their patients) who were interviewed by the researcher after the mutual support group intervention, and the remaining 18 group participants who refused to be interviewed, are tabulated in Table 8.1. When the socio-demographic characteristics of the two subgroups of family carers in the mutual support group were compared, great similarities in all of the characteristics of both the 20 interviewees and the other 18 group participants were found. There were slightly more females than males amongst the carers and their patients, among both the interviewees and non-interviewees. The mean age of the carers in the two subgroups was about 33 to 35 years (SD= 10.3 and 12.1) and more than two-thirds (70.0% and 66.7%) were aged between 20 and 39 years. The mean age of the patients was 25 - 26 years (SD= 8.1 and 7.1) and about 90% of them were aged between 19 and 30 years. More than two-thirds of the carers and 88% of the patients had been through secondary school or higher education. The majority of the carers were spouse or parent of the patient. The patients' mental condition was mainly reported by the family carers, as improved or stable (over 85%) during the previous three months, when compared with the past year. About 88% to 89% of them had either low or medium dosage of antipsychotic medication. The average number of family members living with their patients was about 2.9 (mostly from 1 – 4).

8.3 THEMES IDENTIFIED IN RELATION TO ACCOMPLISHMENT OF THE FIVE STAGES OF GROUP DEVELOPMENT

The development of the mutual support group used in this study was designed in terms of the five proposed stages (refer to Section 4.7 in Chapter 4 and Appendix 4 for details) identified by Wheelan (1994) and Kimberly (1997) through their experiences in therapeutic groups among different family and patient populations. Data from the tape-recorded sessions and interviews revealed that 16 of the 20 family

Table 8.1 Socio-demographic characteristics of 20 interviewees (and their patients) and remaining 18 group participants

Characteristics	Caregivers interviewed (n = 20)		Caregivers not interviewed (n = 18)		All support group participants (N = 38)	
	f	%	f	%	f	%
Family Carers						
Gender						
Male	9	45.0	7	38.9	16	42.1
Female	11	55.0	11	61.1	22	57.9
Age	M=33.9, SD=10.3		M= 35.8, SD= 12.1		M=34.9, SD=11.6	
20-29	8	40.0	7	38.9	15	39.5
30-39	6	30.0	5	27.8	11	28.9
40-49	2	10.0	2	11.1	4	10.5
50-62	4	20.0	4	22.2	8	21.1
Education level						
Primary school or below	5	25.0	5	27.8	10	26.3
Secondary school	13	65.0	11	61.1	24	63.2
Tertiary [a]	2	10.0	2	11.1	4	10.5
Relationship with patient						
Spouse	8	40.0	8	44.4	16	42.1
Parent	5	25.0	5	27.8	10	26.3
Child	2	10.0	2	11.1	4	10.5
Sibling & others	5	25.0	3	16.7	8	21.1
Monthly household income (HK dollars)[b]	M=12,100, SD=1,940		M=10,650, SD=1,760		M=11,500, SD=1,810	
10,000 or below	11	55.0	10	55.6	21	54.3
10,001 – 20,000	6	30.0	6	33.3	12	31.6
20,001 – 30,000	2	10.0	2	11.1	4	10.5
30,001 – 40,000	1	5.0	0	0.0	1	2.6
Number of family members living with patient	M=2.9, SD=1.1		M=2.7, SD=0.9		M=2.8, SD=0.9	
One	6	30.0	6	33.3	12	31.6
Two	7	35.0	6	33.3	13	34.2
Three to five	7	35.0	6	33.3	13	34.2
Patients						
Gender						
Male	9	45.0	8	44.4	17	44.7
Female	11	55.0	10	55.6	21	55.3
Age	M=25.9, SD=8.1		M=25.0, SD=7.1		M=25.3, SD=7.3	
19-24	10	50.0	9	50.0	19	50.0
25-30	8	40.0	7	38.9	15	39.5
31-50	2	10.0	2	11.1	4	10.5
Duration of illness after intervention (years)	M =3.2, SD=1.0		M =3.2, SD=1.5		M =3.2, SD=1.1	
Less than 2	8	40.0	7	38.9	15	39.5
2 to 3	9	45.0	8	44.4	17	44.7
4 to 5	3	15.0	3	16.7	6	15.8

Education level						
Primary school or below	2	10.0	2	11.1	4	10.5
Secondary school	14	70.0	12	66.7	26	68.4
Tertiary [a]	4	20.0	4	22.2	8	21.1
Patient's mental condition after intervention [c]						
Improved	11	55.0	10	55.6	21	55.3
Staying the same	6	30.0	6	33.3	12	31.6
Worsened/Not stable	3	15.0	2	11.1	5	13.1
Current dosage of antipsychotic medication [d]						
Low	10	50.0	8	44.4	18	47.4
Medium	8	40.0	8	44.4	16	42.1
High	2	10.0	2	11.2	4	10.5
Average number of family conflicts per month [e]	M=3.5, SD=1.3		M=3.6, SD=1.8		M=3.5, SD=1.6	
1 – 3	16	80.0	13	72.2	29	76.3
4 – 6	4	20.0	5	27.8	9	23.7

Note: f = frequency, % = percentage, M = mean, SD = standard deviation.

[a] Tertiary level of education refers to studies completed in university and other postgraduate programs in Hong Kong.

[b] US$1 = 7.8 Hong Kong dollars; UK£ 1 = 14.5 Hong Kong dollars.

[c] Family carers' rating of patients' mental condition during the past three months when compared with that before intervention.

[d] Dosage levels of neuroleptic medications were compared with the average dosage of medication taken by patients in haloperidol equivalent mean values in mg/day, as recommended by the American Psychiatric Association (Bezchlibnyk-Butler & Jeffries, 1998).

[e] Average values per month of family carers' self-report of number of conflicts between patients and family members in last six months.

carers perceived themselves as having progressed successfully through the five phases of the mutual support group process. In addition, 12 of the 20 participants emphasised many times in the interviews, that they had developed very good social relationships with other group members; four had formed a close bond with someone who had become an intimate companion and a source of psychological and practical support. Themes that emerged from the tape-recorded data, concerning the positive, desirable changes (also, a few undesirable changes) of personal involvement and commitment to the group and group integrity and cohesiveness, throughout the five phases of group development, are described below.

8.3.1 Building mutual trust and acceptance in the first group phase

Even though three-quarters of the 20 participants were able to work through the first group phase (orientation and engaging; first and second sessions), five of them found some difficulties in getting through the first group phase and, in particular, in building trust relationship with other members and learning to accept their roles and

responsibilities in reciprocal learning and mutual support within the group. They said, in the interview, that they did not find it easy have open discussions about their difficult life situations, or discussing their own personal feelings in relation to caring for their relative with schizophrenia. During the first and second sessions, they also expressed their difficulty in discussing about the effects of the illness on the whole family. As another male carer said, when describing in open discussion, his difficulty with his own family situation:

> "During the first and second sessions, I felt uncomfortable talking about my family and about my son's schizophrenia, and those embarrassing situations which I encounter in my everyday life since my son became mentally ill… I felt that I needed much more time to get used to this group, before I could get to the point where I could trust members enough to have open discussions with them and feel comfortable with my new role and responsibility within the group, which is more than I have ever had to be in my life before." (Interview, Carer 5, paragraph 60)

In the second group session, three other carers also said that they would not be so emotionally involved or time committed with the group. They said they felt very uncomfortable and surprised in the early group sessions, when some members discussed their personal issues and feelings openly and they were amazed that members did not feel embarrassed, even when they were talking about their faults and the times when they were rude to their family and the patient. One of them mentioned that she did not know what she could do to help others, she "just wanted to get something from the group for self, but it turned out to be a 'mutually shared' experience" (Interview, Carer 4, paragraph 31). This carer, like the other four carers, requested more psychological support and information from the facilitator, other experienced carers and professionals from the clinics in the first few sessions.

One female carer admitted that she had had great difficulty in working through the first group phase, and had considered quitting the group after the fourth session. However, she felt able to remain in the group after she had a discussion with, and psychological support from, the group facilitator and another experienced member. According to the interview data, she stated:

> "I felt I could get little help from the group about providing care and I experienced only slight improvements in my family relationships in the early sessions. I could not share my feelings about caregiving with anybody in the group because they didn't seem concerned about my questions and requests, or about my psychological distress. They did not listen to my problems… or any hardship of caring for my beloved husband with schizophrenia, and I felt nobody cared and this was why I considered quitting the group." (Interview, Carer 12, paragraph 42)

After the group facilitator talked to them and some of the other group members discussed the matter amongst themselves, the group came to view her concerns with more understanding and they encouraged her to talk more about her family situation. The group continued to listen and to discuss her problems in the following sessions and when interviewed later on, the carer indicated that she felt "a lot more comfortable". She felt that the care and understanding she had received had helped her to continue attending the support group. She now felt that people were concerned about her situation and, by the end of the third group session, this had given her "a sense of belonging to the group".

Two-thirds of the carers in this study stated that the first and second group sessions were the most important time for them. It was in these sessions that they started to adapt to group behaviour, discussions, and other activities such as social gatherings and, very importantly, they learned to follow its norms. In the third group session, two carers said: "It took time for us to feel comfortable in the group culture and obey the rules, such as open and non-intrusive comments about other members' family events"(Carer 8) and "to participate well in the group activities and achieve our own common goals" (Carer 11). The interview data collected from 10 of the carers suggested that some elements of the group process helped them work successfully to engage with the group and build mutual trust and respect.

The most important element was to open themselves up during group meetings and talk about their own feelings and concerns. This was seen to be the most effective and efficient way of getting them to feel comfortable and involved in the group and, thus, enjoy the mutual support of group participation. As one male carer said in the interview:

> "As the purpose of our participation in the support group is to share our needs and learn from each other, we have to tell each other what our concerns are and share our unhappy and challenging experiences in caregiving, as well as our positive and pleasant ones. If we can't do this, nobody will be able to understand our concerns or identify our problems, or look for alternatives to resolve them, or even assist us in relieving the distress that caregiving causes us. I can understand that some of us are not used to disclosing our personal experiences and feelings, but you know, we are "all in the same boat' and so we should not feel embarrassed at hearing about similar bad or poor caregiving experiences, experienced by others." (Interview, Carer 16, paragraph 68)

This extract highlights the importance of openness by the participants, if the main purpose of the intervention (mutual support and help) is to be achieved. If this is

explained to the group members, they will not feel too embarrassed when relating their personal experiences and the feelings they have about their caregiving.

The second element was to establish a few simple but realistic and achievable goals during the first and second group sessions. This element was identified as one of the positive group characteristics and is discussed in Section 8.4.2. One example of their perceptions of goal setting were:

> "I think it is very important to decide on just a few realistic goals in the first session and then work on them, one by one, in the later sessions. We discussed the feasibility in detail and the time needed to achieve the goals… deciding the most important common problems of patient care provision. Then we worked smoothly and satisfactorily to identify the alternative actions and practised and tested them one by one, at home in our family life. I can't say this is the best way of learning in the group, but it worked for us and fulfilled our purpose of participation in this group." (Sixth group session, Carer 17, paragraph 66).

The final important element of working through the first group phase successfully was the participants' willingness to listen to, and take the initiative in, helping others. As one carer stated during one group meeting, "if we want to establish trust with each other, we have to take the initiative first of all, in listening to the concerns and problems of our group mates and then stretch out a helping hand to assist them as best we can" (Second group session, Carer 13, paragraph 40). More than three-quarters of the 20 family carers, similar to one spousal carer during the interview, emphasised that, "The most important reason for us to continue attending the group was that we felt that the others listened to our concerns and feelings attached and offered each of us practical help if we needed it" (Interview, Carer 16, paragraph 50). Five of them very clearly remembered how impressive the first practical assistance was, that they received from the group, in caring for their patient or other family members, and in managing some household chores, especially when their patient was mentally unstable. For example, one young carer said:

> "It was amazing when a few group members treated me so well that they even helped me to get some household chores done and helped me with patient care. I shall never forget the wholehearted support from my group-mates." (Interview, Carer 10, paragraph 33).

8.3.2 Resolution of power, control and decision-making within the group

The second phase of the support group (third and fourth sessions) was not easy for the family carers to get through, but most of them felt satisfied with the gradual changes that had taken place during this phase. The psychological tensions of group

members were indicated in the interview and group session data, together with how the group managed to resolve their issues of power, control and decision-making. Among these issues, perception of control over events and participation in decision-making were the most prominent and explicitly expressed, within the group.

The struggle for power was not really a problem within the group. As one mother carer said during the fourth group session: "It is really not difficult for me to follow others' instructions and orders, as our family has always been one where family members met and discuss problems together, before making decisions about family affairs." (Carer 17, paragraph 80). Another husband carer supported this idea during interview and said: "I think our group members were able to work together and decide the activities to be undertaken in each session and we seldom had a struggle about one person's power overriding the group decision." (Interview, Carer 14, paragraph 37).

Unlike other social groups, the carers in the mutual support group did not indicate too much concern about power distribution within the group. Most of them were willing to follow the rules and norms of the group, and to allow the co-leaders to plan their discussions. Like most of the group participants, one carer said:

> "It doesn't bother me who leads the group, or who makes the decisions about the format or activities of each group session. The most important thing for me is to be in the group and to learn how to cope with my caregiving role. Whenever I felt I was being most supported, the topic for discussion was always relevant to my caregiving or when, in each session, we were able to talk over our valuable experiences in caregiving. I didn't mind others taking the lead in the group… and I didn't care who was making decisions for us." (Interview, Carer 13, paragraph 39)

However, eight family carers indicated that they sometimes had disagreements and struggles with other group members in the process of decision-making during discussions. This was illustrated by one of them who, referring to the third group session, said that: "Some group members sometimes seemed very unreasonable and authoritative in making decisions about the topics of discussion and did not always make adequate time for me to share about my opinions, before summarised our concerns". However, some of these negative comments and feelings about the ways other members led the group arose from the carers' own preference and style of decision-making. If the carers had learned to consider the preferences, communication and working style of other group members, they might have viewed the perceived 'unreasonable' behaviour in a quite different way. For example, a mother carer (Carer 17) said in a later session:

"I understand that it is very important for us to have respect for each other, and to share information and concerns, and even to leave room for expressions of intense emotions and feelings about patient care. If we only focused on our own concerns and problems, we would not have time to listen to others and learn alternative ways of solving problems from their experiences. I now appreciate much more how patient the other group members were with me in withstanding my self-centredness and unreasonable demands on them, and in listening to what I said." (Seventh group session, Carer 17, paragraph 33)

This extract shows that one of the most important factors influencing individual learning and development in the second group stage is 'altruism', an unselfish regard for or devotion to the welfare of others in a support group environment. This is also considered very important to the decision-making process of the group, and promotes mutual respect and a considerate manner.

Despite the mildness of the power struggle within the group, 18 of the 38 carers preferred to have some control to the way and the extent to which they shared their experiences during each group session. Such decision-making by the members resulted in a more flexible group process and increased team spirit. At the request of some members and the agreement of them all, the group had a short discussion of about 10 minutes at the beginning of each session, about what they were going to do or discuss within the session, and they each took part in choosing some of the activities performed during the session. For example, during the second session, one carer suggested that a few members perform a role-play of a patient being violent in a restaurant, and this was followed with a discussion about the management of patients' disruptive or disturbing behaviour. It was suggested that the carers' wish to have control over participation and discussion within the group was a reflection of their wishes, and also a displacement strategy for having better control over the caregiving situation within their families. As one carer stated in the interview:

"I would like to play a part in deciding the topics or format of the discussion in some of the sessions, but I felt too insecure and uncomfortable to talk about something that I don't want to share with others. Maybe I have already got so many things that I am worried or concerned about, that I don't want to add any more. At the very least, I need to know what is going to happen during the group meetings so that I can feel confident enough to attend the group... Similarly, it would be wonderful if I could have the chance and ability to decide on my family activities." (Interview, Carer 20, paragraph 33)

Similar desires and expectation by the family carers to be in control over decision making in their own group activities was also identified in the group session data. For example, in the sixth session, one spousal carer stated that:

> "We have more control over events in the group than we have over our own families and I think this is important to group members because it gives us a sense that we are perhaps regarding control over our whole life situation" (Sixth group session, Carer 16, paragraph 71).

Twelve family carers were identified from the verbatim data taken during the fourth group session, as understanding what one female carer said was: "This mutual support group had a level format where every participant had an equal right to discuss about their needs and problems; and there was little or no concern about authority or power holding, or about who led and directed the group" (Carer 10). These data showed that, as long as group members could help each other to cope with caregiving, they seldom raised any concerns about their lack of authority within the group. Indeed, they wanted to have even more opportunities for participation in the decisions about the group events.

8.3.3 Learning to adopt new coping methods and skills in caregiving

For the third and fourth phases (fifth to 11th group sessions), the mutual support group appeared to run smoothly and make good progress in dealing with their major concerns about caregiving. Eleven of the 20 family carers indicated during the interview, that they had gained "more understanding about their relative's illness and its related behaviour" (Carer 13, paragraph 38), and they were able to recall different ways of dealing with their negative emotions concerning their patients in real life practice, and found them mostly effective. During the sixth group session, five of them admitted that they sometimes had difficulty in applying their newly acquired coping skills to their real caregiving situations. However, on many occasions within the group sessions, the other 15 carers (interviewees) emphasised that they had experienced more effective communication and improved relationships with their patients and other relatives, following the fifth sessions. This was reflected in their pleased smiles and their reports of some of the joyful interactions and activities they had had with their patients after the group meetings.

Coping with their caregiving role was found to be very difficult and challenging for more than 10 family carers who spoke of this during their interviews, especially for seven of them who had limited social support from their family members. However, these seven carers were the most regular and active participants in the support group and, when interviewed, they said they had gained "much benefits from the reciprocal psychological and instrumental approach of their participation in the group" (Carer 10, paragraph 28). Moreover, these carers

also showed significant improvement in their psychosocial condition as well as in patient functioning, at the post-tests, when the outcomes of their group participation were examined. After the seventh session, 15 carers reported that they were able to communicate better with their patient and also had better understanding of the illness. As a result, one carer said: "I no longer blame the patient for the disruptive or annoying behaviour they presented" (Carer 17, paragraph 77).

However, despite all the things they learned from other carers, such as how to cope with the stress of caregiving and how to use problem-solving approach in the management of their patient's problems and demands, the carers felt they required much more 'behaviour rehearsals' and practice in their real family life. Some of the carers found these skills difficult to learn, especially those (four carers) who had only taken up their caregiving roles a few months earlier, and a further seven admitted that they had limited knowledge about the illness and its treatment before participating in the group. In the 11th group session, one female carer who had shown a mild improvement in her psychosocial condition at the first post-test said:

> "I really did not know what exactly schizophrenia was before participating in this group. Nobody told me how to take care of my father who had originally presented with absurd, agitated and disruptive behaviour. Teaching or encouraging my father to take his medication had also been a big problem for me… because I did not know the effects of the drugs. Therefore, I needed much more time to take in all this knowledge and to learn the skills relating to the care of my father. I was able to practise some of the skills I learned in the group, but have not been able to put them all into practice in the past few months… I think this difficulty in using all the things I learned in the group may have been due to my lack of experience and knowledge in caring for a mentally ill person." (11th group session, Carer 17, paragraph 60)

This extract highlights that family carers can learn about the mental illness and coping skills for caregiving from a support group, but they learn at different speeds and to different levels, according to the degree of their involvement in the group and their previous caregiving experience. Members of the mutual support group should remind each other to monitor the progress of individual members and provide specific attention and assistance to those who cannot adapt efficiently to the group's activities and mutual support.

However, most of the carers stated that the number of sessions held to help them learn new coping skills for caregiving and the length of each session (about two hours) were appropriate for them. In the eleventh session, they suggested they would like to have extra support and social activities outside the group meetings, such as "some practical assistance in caring for their patient or frail family member at home, provided by a few close-linked group mates" (Carer 5), or "an informal telephone or face-to-face contact

every week to meet the others and tackle some immediate problems that have arisen in-between the two group sessions" (Carer 12).

8.3.4 Preparation of group members for future life with adequate support

During the last session (and part of the eleventh session), specific time was set aside by agreement of all the group members to evaluate the results of their learning and goal achievement within the group, in preparation for the dissolution of the group, and to discuss related issues such as their emotional reaction towards the forthcoming termination. The importance of independent living and use of problem-solving skills was stressed, especially for the six members who would not be continuing their participation in their self-initiated support group set up for a few close friends among the group members, at the close of the study. Fifteen of the 20 family carers at the interviews felt very satisfied with what they had learned about caring for their relative with schizophrenia and with the consistent support they had received from other group members. They also expressed satisfaction with the mutual aid and support amongst group members, when working on common goals, agreed tasks and also on some of their own personal concerns. Five of them emphasised that the most important outcome for them was the "true friendship" they felt they had established with other group members. They felt this intimate, personal relationship would be of much value to them in the future.

Termination of the group and separation from many of the other group members created high levels of anxiety to six interviewees and, in particular, to four of them who had been regular attendees and had built up good relationships with many of the others. However, they found that "the anxiety and uncertainty was reduced after we had talked about it with the others in the last group session" (Interview, Career 19, paragraph 44). One young carer also suggested that a brief summary or evaluation could be organised in the seventh session, in order to "consolidate what we have learned and to discuss what we expect to do in the coming sessions" (12th group session, Carer 14, paragraph 90). Five other carers supported this suggestion and agreed that such a consolidation could help them reduce their uncertainty about what would be doing in the final five group sessions and "prepare us psychologically to accept the closure of the group" (Carer 4, paragraph 102).

Assessment of their own problem solving skills and ways of coping with their caregiving role, combined with the support and encouragement of other group members, were found to be effective in reducing their anxiety and in helping them feel more confident about their future independence and caring abilities. As one male carer said in the last group session:

> "I was only able to feel secure because I made an agreement with my close friends during the last group session, that we would offer continued support to each other after the intervention. In addition, we knew the facilitator could also be contacted for any professional advice if we needed it. For me, the most important thing is to be able to contact somebody for help whenever there is any great difficulty or problem within my family in the future." (12th group session, Carer 6, paragraph 75)

These extracts show that the final, closing stage of the intervention was very important for most of the 20 group participants, as it enabled them to review all that they had learned and to prepared, not only for their separation from the other members but also to set up a small peer group for friendship and support with the group members to whom they were closest. The 20 interviewees all agreed that such a small self-help group might be "flexible in time and format" (Carer 10) and "better focused on individual family caring needs" (Carer 11).

As requested by the family carers in the pilot study, an additional group session was conducted for five of these 20 carers to better prepare for their independent use of problem solving and future life. They indicated in the interview that this extra session upon request was very important and helpful for them to terminate the group participation, "ascertain my competence in caregiving" (Carer 7) and "motivate our engaging to other family support services appropriate to us" (Carer 14). However, the other 15 interviewees had been asked whether they were in need of this and they would not be available or preferred not to attend any additional session. Therefore, this indicates that an additional session for preparation of group termination could be considered for the mutual support group participants on an individual basis.

8.4 PERCEIVED BENEFITS AND DIFFICULTIES EXPERIENCED BY THE CARERS FOR PARTICIPATION IN THE SUPPORT GROUP

In addition to the themes identified in relation to the accomplishment of the five stages of group development, the data of the interviews and group sessions also revealed important themes that were perceived by the carers to have contributed to the benefits they gained from their participation in the group and which they believed influenced the success of the mutual support group in this study. These themes grouped under three headings: individual, group and social environment. The clear account of the procedure used in thematic analysis of the data of the interviews and group sessions and of how the main themes emerged, together with the examples used to illustrate them, can be seen in Section 6.10.2 in Chapter 6 and Appendix 11. The

main themes for individual, group and environment levels and their related categories or sub-themes, are all tabulated in Table 8.2 and discussed in detail below.

8.4.1 Theme 1: Individual changes in role identity, perception and coping ability

The first theme to emerge from the data of the interviews and group sessions was the way each individual family carers changed, due to their group participation. These included: their view of their role, their perception of the illness and their method of

Table 8.2 Major themes emerged from the qualitative data - interviews and tape-recorded group sessions

Themes	Categories/ sub-themes
8.4.1 Individual changes in role identity, perception and coping ability	• Changes in personal identity in relation to family caregiving • Changes in perceptions of mental illness and its care • Adoption of new role and effective coping skills for caregiving
8.4.2 Positive and negative group characteristics	• Positive group characteristics - Explicit group ideology and consensus in early group stage - Relational social climate ❑ sense of cohesiveness ❑ goal (task) orientation ❑ openness of self in sharing of experiences - Informational support and empowerment • Inhibitory factors influencing group development and its success - irregular or low group attendance - negative and high peer pressure and dominance in group - over-expression of intense negative emotions
8.4.3 Importance of the structure of and the external support for the group programme	• Impact of a non-hierarchical and autonomous group structure • Importance of professional involvement and support • Social support from family members and people outside group

coping with careigivng. The three sub-themes of individual changes influencing the success of a mutual support group, as perceived by the family carers themselves, included changes in self-identity (image) in relation to caregiving, changes in their perception of mental illness and adoption of new and effective roles and coping skills in caregiving. Despite different levels and rates of changes amongst the group

participants, all of the family carers in the support group expressed at least some of the three aspects of change, as revealed by the discussions during the group sessions and the interviews, as described below.

Changes in personal identity in relation to family caregiving

The family carers in this study, like those reported in previous studies of families with schizophrenia, experienced feelings of loss, uncertainty, and also emotions of shame, guilt and resentment when they had to take up responsibility for caring for their relative with schizophrenia. Illustrating this, one female carer said in the first group session: "I feel loss and don't want what I can do to improve my family situation to be put at risk just because I have to provide care for my ill relative" (Carer 3, paragraph 70). For various reasons such as poor relationships and upbringing, or through biological inheritance, they said they were being made to feel that "the mental illness in my family was all my fault" (Second group session, Carer 7, paragraph 12), and, like their patients, they felt that they were being "stigmatised by our neighbours as being equally disturbing and dangerous people to have in the community" and "disliked and socially isolated by most of our relatives and friends" (Interview, Carer 9, paragraphs 30 and 48, respectively).

Most carers emphasised that one of the major benefits to them of group participation with such deviant labels, was the way being in the group enabled them to construct "a new and positive caregiving identity" (Carer 12), which they saw as positive and reassuring and to which, they attributed the improvements in their psychological state. Ten carers said that they were able to identify with other group members, because "we are all going through the same stressful experiences of caregiving, and are 'in the same boat'" (Interview, Carer 10, paragraph 30). Gradually, they recognised that they too could achieve "what the others had achieved in caring for their patients" (Interview, Carer 18, paragraph 40). By recognising these small but important achievements, they said that: "we are more positive now about our self-image, in spite of having to take care of a relative with schizophrenia, all alone, for the foreseeable future" (Fifth group session, Carer 20, paragraph 68). These 10 carers who showed mild or significant improvements in their psychosocial health, following group participation, felt more positive about their own identity because they had "a better understanding of the importance and responsibility" in caring for the patient (Carer 20)

and "would not accept that it was the inadequacy of my care for the patient, that caused the illness" (Fourth group session, Carer 12).

The 10 family carers and the other group members showed the improvement in their self-image in different ways, depending on the level of their psychological well-being and the extent to which, individually, they were succeeding this change in their self-image or role identity, was being able to see the possibility of having a meaningful life of their own, even though they had to live with unresolved difficulties. During their interviews, nine family carers suggested that this re-definition of their life's meaning was acquired through their group membership and the repeated practice of the things they were learning from other group members. An example of one of these insights came from an interview with one mother carer who said:

> "Life had been the pits for me in previous months. I had been feeling lonely and guilty ever since my family recognised that one of our beloved family members had become 'mad'. Although my friends invited me on outings and to parties, I did not want to go and meet with them… However, after joining this group, I realised that I had to rebuild a more 'normal' and healthy life for myself, and reach out to others. I could not just stay with my beloved son and let myself become socially isolated, powerless and helpless. I thought I should do something to improve my life. And, this has enhanced my motivation in taking care of my son." (Interview, Carer 7, paragraph 30)

Eleven of the group participants expressed similar ideas in the group sessions as the above extract, and the following comment from one male carer in the eighth session illustrate the carers' gaining insight into their own life's meaning:

> "I had a lot of problems in performing my caregiving role and some of them will never be resolved… the fact that my relative has schizophrenia and that this can never be changed and that she will probably have this illness in a long period of time. I shall always have to take care of her and I won't leave her alone… From participating in the group, I learned that the best thing I can do to continue providing care for her is to keep myself physically and psychologically healthy… and it is no good continuing to blame my daughter for her illness …" (Eighth group session, Carer 11, paragraph 92)

Changes in perceptions of mental illness and its care

More than 10 family carers, who originally felt they had insufficient knowledge about mental illness and who, prior to their participation in the group, felt diminished by their misunderstanding of the illness and the psychological distress of caregiving, changed progressively to the point where they were able to make sense of the reality of the illness and were then able to find better reasons for their responsibilities and their difficulties in caring for their patients. What one husband carer said in the interview illustrated this:

> "In the past, I did not understand what schizophrenia was. I felt a bit scared and hesitated to take up the caring role for my wife with this illness. I asked the staff in the clinic a number of questions about how to take care of my wife… but I was in the dark. I learned a lot from our mutual sharing in the group and the help I received. I understood more about my caregiving situation and this was true, not only for me, but also for all of us in the group. I also learned that the difficulties I had encountered had been experienced by other carers as well." (Interview, Carer 9, paragraph 52)

Another verbal comment given by one female carer in the sixth group session was consistent what the other six carers said, and also illustrated the importance of information given by the support group about schizophrenia and its care. She said:

> "In the previous five sessions, I was able to find out a lot of important information about schizophrenia and its care from the other group members. We also shared various experiences in caregiving and whether these had been successful or had failed. We learn a lot from sharing this information. Most of the group members are now able to accept their caregiving role… without too many complaints or dissatisfaction. As a consequence of this, I felt I needed to ask myself why I couldn't accept my situation and responsibility of caregiving." (Sixth group session, Carer 17, paragraph 66)

This extract also highlights the fact that the information about the illness and sharing the caregiving experiences of family carers in the support group, could change and increase not only the participants' understanding of the mental illness and its care but also their own caregiving role and their sense of responsibility about patient care. These changes are consistent with the purpose of the family support group, and were also expressed by six family carers during the later group sessions, who said that "this support group can be seen as an attachment of group members facing a similar set of life problems, in which we are helped to improve our adaptation to and skills in dealing with the short-term crises" (Carer 3), as well as with "the long-term challenges and privations, inherent in our caregiving" (Carer 5).

Importantly, during their group participation, the family carers realised for themselves that these changes in their perceptions of the illness and its care, were related to the dialectical process of the support group or, as suggested by one carer:

> "Each group participant had a chance to think about the different experiences, ideas and ways of caregiving used by other group members. We were also able to discuss about the pros and cons of these different methods, with mutual respect and trust in each other. I felt so secure during the group meetings that I found I was able to talk about my family's affairs and conflicts without any fear of being criticised, laughed at, or having what I said widely disseminated to other people outside the group." (Seventh group session, Carer 16, paragraph 56)

In addition to 'letting go' of their pointless or unsuccessful ways of caring for their patients, the family carers learned to re-define their patients' problems and, thus, their own way of coping with them. During the last group session, five carers mentioned that this way of reframing their view of own life's problems was reflected in the statements they made when talking about their learning. For example, one mother carer said:

> "I learned to articulate the correct ways of handling the upsetting events that occur with my son, which I have usually avoided and denied in the past. I try to think more positively now and to remain calm when facing these difficulties and to accept them as something that is unlikely to change." (12th group session, Carer 1, paragraph 37)

Six of the 20 carers who had shown improvement in family burden and functioning, indicated that they had learned to correct openly anyone they heard inappropriately managing the patient's annoying and embarrassing behaviour. They managed to exchange ideas and opinions without fear or any feeling of trespassing on the personal affairs of others, even though sometimes conflicts and misunderstandings arose during the ensuing discussion. The successful resolution of conflicts between the group members, with minimal assistance from the facilitator, reflected the positive cohesive forces within the group. This can be illustrated by what one carer said:

> "I don't mind my actions and behaviour being thought of as 'wrong' or 'irresponsible'. Everyone shared their embarrassing behaviour and admitted their faults to each other. I think this has been a good way of learning how to accept others and to feel accepted ourselves." (Interview, Carer 12, paragraph 33)

These extracts highlight how successfully the carers had reframed their life problems and pinpointed what was wrong with their management of their patients. They also indicated a relief of the burden of being a victim themselves or of the necessity to accept the blame for their relative's illness and, thus, they began to act compassionately toward the sick relative and had a more positive view of mental illness generally. For example, one father carer said in the interview:

> "I understand that I cannot change the fact that my son is suffering from schizophrenia but, since my participation in the group, I have been better at managing my son's care. I am now working very well with my family to help my son improve his mental health problems. Similarly, some of my group mates told me that they, too, felt more secure about their own life situation. They felt more positive about their caregiving and also the improvement in patient's mental condition." (Interview, Carer 12, paragraph 80)

Nevertheless, the other five interviewees who had shown either mild improvement or deterioration in family functioning over the follow-up period,

continued to find their relative's behaviour annoying and they admitted that they were unable to fully accept open discussion about their adverse family situations. The five carers said that they sometimes found it difficult to accept the open personal disclosures of the others in the group and they thought they might need more time before they could fully adopt this attitude and start practising self-disclosure.

In addition, three of them continued to focus on trying to find the cause of their patient's illness and were still finding it difficult to adapt to their own situation, despite having gained more understanding about the illness. These three carers also indicated in the group sessions that, although they understood more about the illness as a result of being in the group, they still "could not accept" that the illness had occurred in their family, or that "long term care would be needed" for their sick relative (Ninth group session, Carer 13). Another carer said that both she and her family "still felt guilty and concerned about the mental illness that our relative was suffering from", and although the group "had helped us clarify some of our misconceptions, it had not clarified them all" (Tenth group session, Carer 10). These extracts indicate that some of the family carers might require a longer period of group development and learning, or more intense and individualised support. A minority of support group participants, like these carers, might still feel that they were to blame for their relative's illness and suffering, and feel guilty. If this was so, they would only gain limited benefit from their participation in the group.

Adoption of new role and effective coping skills for caregiving

The final category that emerged from the data regarding the ways how the carers viewed the changes in their own caregiving attitude and behaviour, was the adoption of a new role and effective coping method of caregiving. As a result of imparting information and disclosing different perspectives of caring for their relative with schizophrenia among the group participants, including informational, psychological, interpersonal or personal ones, the family carers gained at least some experiential knowledge from others who had lived through and resolved their life problems and, this knowledge would probably not have been purely from the expertise of health professionals. The carers were able to see that such experiential learning came from group members' personal stories. They started with communicating with their patient and other family members, with the support of the group environment, and continued by listening to and understanding how the other group members had attempted different means of communication and then by resolving any arguments or

conflicts among family members, that had arisen from unclear communication and misunderstanding.

Ten of the interviewees suggested that this way of sharing would be "a good demonstration of the group members' care and concern for each other" (Carer 10) and, at the same time, a means of "practising effective communication with people" (Carer 16). In addition, more than 10 carers also told other group members many times, in different group sessions, that they had learned several effective ways from the group, of communicating with their patient and other family members and that they perceived that they were now "playing a new role as a caregiver, who thought and talked in a more positive way about the illness and provision of care for the patient, than they had before joining the group" (Carer 14). The suggestions made by the group and the opportunities to practise with them alternative styles of communication and ways of interacting more effectively with their patient and other family members, and learning to deal differently with problems and conflicts within the family, were looked upon by these carers as very important in their adoption of a new caregiving role. One example to illustrate this relationship between learning ways of effective communication in the group and adoption of a new caregiving role was:

> "As a result of repeatedly practising the new methods within the group, we found we were able to communicate more effectively with patient and other family members and this, in turn, gave us more confidence as family carers…" (Ninth group session, Carer 20, paragraph 76)

When it came to effective coping with patient care, about two-thirds of the 20 carers indicated the importance of different effective methods of coping that they had learned from other group members. They said that, for them as carers, "learning coping skills for caregiving was one of the most important components of the support group's work" (10th group session, Carer 10), and much time in the group sessions was therefore allocated to "discussion and role play about alternative methods of coping with difficulties in their patient and family care" (Seventh group session, Carer 5). For example, during the interview, a spouse carer stated one way of effective coping with patient's symptoms that she had learned from the group:

> "I have learned to soften my tone of voice and avoid arguing with my husband (patient) when I see him suddenly shouting and talking to the air. I could not stay calm in the past, but I now understand why he behaves like that and I appreciate that he has suffered a lot from this and all his other symptoms. I feel I have to assist him in overcoming the disturbance created by his symptoms and all the worry and sorrow which have resulted from them… they are not what they wanted, nor are they their fault. I think learning this during my participation in the group has been of great importance to me." (Interview, Carer 5, paragraph 42)

However, throughout this six months' group intervention, it was found difficult for three of the 20 carers to discuss the 'taboo area' of their family life, particularly as they only met four or five times out of the 12-session programme. The 'shared personal secrets' and the willingness to share their own secrets were seen as the basis for the formation of a trusting relationship and an open disclosure among the group members and, thus, were crucial in enhancing their cohesiveness. However, four carers suggested that more work could be done to facilitate this sharing of personal coping skills in caregiving. For example, having more discussions about the scenarios they encountered both inside and outside the group meetings and organising more outside group contacts and social activities might also facilitate and strengthen this sharing and help to get over their internal 'scarlet letter'. Despite the difficulties in sharing personal events during the group meetings encountered by a few participants, the majority of the family carers said that "many of these personal but important issues could be talked about within the group, where there were others who had similar life situations" and most of them were able to "accept and understand each other's concerns and difficulties in caregiving" (Carer 8) and, beyond that, "through the mutual learning and support in group discussions, we were able to help each other regain self-respect and esteem" (Carer 18). The family carers found that these personal experiences provided better insight into how to provide more effective patient care and helped them to cope with the difficulties and problems they encountered in caregiving.

8.4.2 Theme 2: Positive and negative characteristics of the mutual support group

The second theme that emerged from the interview and group session data and is related to other group-level factors, was the positive or negative characteristics of the mutual support group perceived by the family carers to be important for optimising their participation and the mutual benefits gained from it. Three of the most important positive characteristics concerning the development of the support group and its participants were: the explicit group ideology and consensus in the early stages of the group, the group's positive social climate, and the informational support and empowerment. On the other hand, there were three negative characteristics concerning the support group, which were perceived by the carers to be inhibitory factors or barriers that they felt militated against the development of the group and against the benefits that the family carers might derive from it. The major inhibitory factors identified from the data included: low or irregular group attendance, negative pressure

from dominant experienced members and over-expression of intense and negative feelings during group meetings. These major characteristics are described below.

Explicit group ideology and consensus in early group stage

The first positive characteristic mentioned by the carers (group participants) was the establishment of explicit and realistic group ideology and consensus during the early stage of the support group. All of the 38 carers in the first and second group sessions very much valued the fact that the support group thoroughly discussed their expectations about the group, their common goals and the objectives of the carers' participation in the group, the guidelines for the behaviour of the group, and the appropriate ways of expressing ideas and comments. Five of them indicated that, with the guidance of the facilitator, they "would take the agreed rules and goals seriously" (Carer 5). It also appeared that the other carers very much agreed with this intention and asked the facilitator to remind them whenever they failed to show this mutual support behaviour. For example, one young female carer indicated a strong and explicit group belief in the first meeting as follows:

> "We should remind ourselves that our common goal is to promote mutual help and support amongst us, in order to help us live more happily and harmoniously with our family. We should all try to absorb group ideas, not just stick to our own way of doing things and, as a living reality, we have to face daily challenges and learn how to live with a lot of unresolved problems." (First group session, Carer 15, paragraph 50)

From the interview data, 13 of the 20 carers expressed the positive effect of having a simple and achievable mutually agreed goals and set of objectives. This was illustrated by one sibling carer's comment:

> "With a simple, realistic goal and direction set in the first session, our group members cared for each other wholeheartedly. I really experienced release from the horror of the distressing events mentioned by the other families or friends in the group, and from the crushing blow of my own loss in caring for my daughter (patient) in the last discussion. I learned to not only centre myself on their pain, but also to reach out to them in empathic ways." (Interview, Carer 13, paragraph 61)

It is also interesting to note that more than half of the group participants gradually created a set of views and beliefs about their participation in this support group, through repeatedly testing the behaviour and responses of other group participants, and through self-evaluation by comparing their lives with the lives of the other members. The emergence of changed views concerning their participation in the group was found to parallel the five proposed stages of group development (see Section 4.7 in Chapter 4). With such explicit agreed goals, about 30 of the 38 carers

indicated, in the group sessions, that their close relationship with the support group and their belief in the purposes of the group changed from the beginning when comments such as "I am not sure of the usefulness of this group to me" (First group session, Carer 4) was made, through the in-between stages such as "Sometimes, I can contribute to the group and share my feelings and opinions, but I can't always do it because I can't completely accept the open discussion and challenges" (Seventh group session, Carer 8), and to the final full commitment of "we looked back at what we used to be like and we can think positively about how we are now" (11th group session, Carer 7).

Nevertheless, these positive significant changes were not found similarly in all the remaining eight carers who had merely been attracted by the supportive group climate and only started to open themselves up and share personal concerns near the mid or end phase of the support group. These slow-to-warm-up participants felt that they needed more time before they were able to be more actively involved in the group. This was illustrated by what one female carer said:

> "I needed more time to be involved more actively in my group. If the group sessions could be spaced out, for example three weeks apart in the later stage, or if there were more than 12 sessions, I might have had more learning from the group and more home practice and, thus, more positive changes in my beliefs and behaviour in caring for my relative with schizophrenia." (Interview, Carer 18, paragraph 38)

Perceived positive relational social climate

The second positive group characteristic was the relational social climate within the group, which was perceived by the group participants as constructive and conducive to the benefits they obtained and the positive outcomes resulting from their participation. This positive group climate included three elements: cohesiveness among group members, task (goal) orientation and openness in discussion; and they are presented accordingly as follows.

Thirteen of the 20 carers (interviewees) showed the satisfactory unity and coherence that existed amongst them, by demonstrating their commitment to the group and friendship for one another. They perceived this friendship as similar to "being one of my first-degree family members and close friends" (Eighth group session, Carer 11). They sometimes assisted another member to settle housework and family affairs outside the time of group meetings. One male carer was so impressed by the friendliness and practical help he had received from a few group members that he said:

> "I did not expect such great help from my friends (group members). They helped me to clean furniture and rooms and move house, and even brought my son back from school for me when I was sick. This practical help was very important in teaching me how to offer help and support to others, instead of just receiving assistance for myself." (Interview, Carer 16, paragraph 33)

These 13 carers also indicated, in both the interviews and group sessions, that this sense of unity and cohesiveness came from the experience of communality they found within the group, mainly because others had "similar experiences, feelings and questions as us" (Interview, Carer 11) and the feeling that "you are not alone; others in the group have also encountered and understood your problems" (Interview, Carer 19). In the group sessions, these carers also recognised the benefits they derived from this feeling of togetherness or, as they expressed it "having an understanding of everybody else's situation" (Carer 11), feeling that "everybody belongs to the group" (Carer 16), and the empathetic "feeling of being understood" (Carer 10), as they recognised other members' support for their role as a primary family carer, who were "willing to share their views in caring for their sick relative" (Carer 12).

From the group session data, it was also found that five participants, who had interacted actively and freely during most group sessions, were able to alter one another's attitude by their interactions and these carers, with their pleasant personalities and positive actions and ways of thinking, had an important impact on the other members. For example, one older carer said: "I was so impressed when other members shared with me frequently and assisted me repeatedly in finding an effective way of caring for my son." (Sixth group session, Carer 19). This impact was endorsed by what they said in the interviews when, for example, one sibling carer said:

> "I learned a lot about caregiving from communicating with those enthusiastic group mates during and outside the group sessions. Their valuable experiences and practical help they gave me, could not have been obtained from other sources, not even from the health services available in the clinic." (Interview, Carer 20, paragraph 50)

However, this strong sense of group cohesiveness and commitment was not felt equally by all the group participants and particularly not by those seven carers whose attendance at the group sessions was inconsistent and infrequent. During the interview, these irregular and infrequent group attendees explained that what they wanted from their participation in the group was: "to learn how to take care of our relative (patient), but without having to spend additional time with other group members outside the group meetings" (Carer 14), even though they knew that "learning to care for the

patient should not be confined to the time of meeting" (Carer 4). It appeared that this relatively low level of commitment might be related to the inability of these members to adapt to the demands of other group members and, particularly not to the outside group meetings or to the reciprocal 'give-and-take' relationship within the group, which were regarded as "constructive and productive group culture" by other carers.

Despite the fact that most of the carers were able to accept the 'give-and-take' principle agreed by all group members, the demands of mutual help and concern for others during the group participation sometimes overwhelmed the participants and made them question how much benefits they were actually gaining from the group. This was reflected by one wife carer in her interview who said:

> "There should be more time and opportunity for resolving our problems, or for letting others care for us. I sometimes felt overwhelmed by everyone else's problems, on top of my own. I suggest that time should be allowed by the facilitator, guest speaker or experienced carers, in each group session, for information on how we can make best use of the information we have been given." (Interview, Carer 16, paragraph 59)

The extracts cited above highlight the degree to which the group needed to give assistance and take care of others' concerns first, even if, sometimes, their own needs were sacrificed initially. This principle of 'mutual concession' was considered to be an important factor influencing the development of the support group and was mostly to be observed among those who attended the group regularly and who actively entered into the group's activities and discussions.

The second element of the support group's positive relational climate was task or goal orientation. This related to the amount of emphasis that members placed on learning practical problem solving and coping skills for caring for their patients during the group sessions. The support group was described by 10 family carers as "a well-received group programme". It was "orderly", "well structured and systematic", and "problem and skill-focused". These carers also stressed the importance of finding out whether the different methods of patient management, suggested by the group members, were effective in practical use. In general, they expressed appreciation towards the group, as one young male carer said:

> "The group served as a 'healing agent' in helping us to deal with our own unique family problems... It was good to know that I was not the only one who had been through such problems... and there might be answers to my troubles." (Interview, Carer 1, paragraph 62)

The positive partnership relations between the patients, their carers and the facilitator, especially in the few sessions when the patients were invited and encouraged to participate, clearly showed the usefulness of the support group in solving the problems. The facilitator and the experienced carers were able to engage directly with the patients and see, at first hand, how their relationships worked with their family carers. They were able to invite the cooperation of both sides and clarify some of ways of working together so as to enhance the possibility of recovery from the illness. What one carer said in the interview was a good illustration of this:

> "We found that the collaboration between the carers, the patients and the group facilitator, in caring for the patients, came naturally in those group meetings. We were able to open up while they were present in the group and establish ways of managing our caregiving that are more holistic, in the sense that we were shown how to connect better with our patients. This was because the primary carers were able to deal directly with their patients, under supervision by the other carers and the group facilitator, and thus were able to make changes in agreed ways, when it was helpful to do so." (Interview, Carer 4, paragraph 29)

It was also interesting to find that those carers experiencing more stressful events in caregiving, and greater resultant distress, were more likely to attend the group regularly and to actively ask for help from other group members and the facilitator. When they had experienced more psychological reassurance and practical help from other group members, they became more involved in the discussions and in sharing. This positive cycle existed in the support group to such an extent that the group became an attractive place for these carers to go, especially when they understood that "the group really did want to help us resolve our difficulties and reduce our frustrations and other negative emotions" (Fourth group session, Carer 16, paragraph 33).

Eight of the 38 carers admitted that they found it very stressful providing care for their patients, although these carers were also found to be amongst those who were most actively engaged and committed to the group activities and discussions. During the third group meeting, two of them said to the facilitator that they felt their stress "was much relieved" after each group session and that they were able to "go back home and interact with my mentally ill relative more effectively" (Carer 11). Another carer said that she "felt accepted by the other group members, even when she had little or no success in using their suggestions" (Carer 14).

This bonding between group members appeared to develop gradually, keeping pace with the achievement of goals in the group, as a result of their ongoing psychological support and practical assistance for each other and they made special mention of this in the last group session, as one female carer said:

> "I was not aware that the gradual development of our relationship would be so intimate and important right now. I mostly focused on our discussion and resolution of the difficulties and problems during group discussions... it wasn't until I thought about the past six months in the group and all we had talked about and done for each other, that I really recognised how much we had understood each others' needs. It was as if we were all one family and everybody else's concerns were also mine. Similarly, all my concerns regarding my family were the concerns of other members." (12th group session, Carer 16, paragraph 72)

The final element of the relational social climate was the openness of group participants in sharing their information and feelings, followed by the reciprocal psychological and instrumental support, which was considered such an essential part of the therapeutic climate of the support group. The degree of openness appeared to relate to the level of disclosure among the group participants and the emphasis placed by the group, on freedom of action and sharing of feelings. Fifteen of them indicated in the group meetings, that they were willing to talk freely to the group about their stressful family events and even "to talk about some of the more embarrassing situations we encountered after we had joined the group" (Fifth group session, Carer 5). Due to the trusting relationship that was being built in the early stages of the group, more than 10 family carers also indicated in the group sessions that they could "feel the freedom of action and expression and the lack of any negative feelings or discouragement from the group" (Eighth group session, Carer 10). This satisfaction was illustrated by what one male carer said in the interview:

> "I felt I was respected and cared for in the group and so I felt free to talk out my concerns and feelings regarding my care of my sick relative. If I or anyone in the group felt sad, we could cry and our friends in the group would give us comfort and reassurance. Nevertheless, I had to tell the others what had happened to me or my family, otherwise, I think they would not have been able to help me." (Interview, Carer 5, paragraph 54)

However, five of the 20 carers (interviewees) indicated that conflicts and negative comments from the group were sometimes not acceptable. When such conflicts arose, they did not know how to deal with them and the facilitator would have to call a time break to settle those arguments where very strong emotions were involved. Although most conflicts were settled, some of them may have caused

members feelings of disappointment with their participation in the group. In line with five of the other participants, one said:

> "We lack the techniques and strategies to resolve these conflicts. I think the group should spend more time in tackling the conflicts, although most were trivial. Nevertheless, the group facilitator had taught us a few methods and skills for managing conflicts, and these could be useful when we are caring for our ill relative." (Seventh group session, Carer 20, paragraph 105)

In the interviews, three carers also stated that some conflicts among the members might be due to "the freedom to speak out and tell others our feelings and opinions" (Carer 20, paragraph 69). They also said they felt "satisfied with the assistance which had been provided by the facilitator in resolving most of the arguments" and "in settling our emotional reactions" (Carer 13, paragraphs 37 & 40).

Informational support and empowerment

The third positive characteristic of the support group was the informational support and feeling of empowerment that was derived from the social support and nurturing within the group. Fifteen of the 20 participants agreed that they had received lots of useful information from both the experienced carers and the facilitator, about the mental illness, its treatment, medications, and patient management, using various means such as newsletters, mental health education leaflets and brochures, videos, and oral presentations. More importantly, the carers found that "group members were able to share both their knowledge and their unsuccessful experiences in patient care" (Interview, Carer 3, paragraph 57) and the carers all understood that this information and advice provided them with valuable tools for the provision of daily care for their relatives with schizophrenia.

Despite two family carers feeling that they had not received adequate information in the group meetings, the remaining 18 carers confirmed, during the 10th to 12th group sessions, that they "had enjoyed learning the up-to-date and valuable information, from the other members in the group and, also, from the guest speakers and the facilitator" (Carer 16). However, they also raised the importance of carers using self-help and their own initiative to search for additional useful information and resources. This important idea was best illustrated by what one young carer said:

> "I was pleased that the group had given one of us so much useful information about the illness. However, I have to say that it is equally important for us to have high degree of initiative for ourselves, to look for up-to-date, useful and appropriate

> materials, for our own support and care. I think this enabled us to help ourselves and live a more independent family life." (Tenth group session, Carer 10, paragraph 77)

The feeling of empowerment, that would allow the families to help themselves, grew as the carers learned about caring for their relatives with schizophrenia from the other group members. The skills were the same that these other members had used effectively in their own families' lives. More than 20 of the 38 family carers said in the group sessions that, they became highly motivated afterwards and wanted to "reach out to people both inside and outside the group" (Carer 10), "to help them, step by step, to tackle their problems over patient care" (Carer 20), and "to manage their feelings of frustration and denial in relation to caregiving" (Carer 13). These 20 carers admitted in either the interview or in the later group sessions, that they had been encouraged by other group members to see clearly that "all of us were suffering from similarly difficult life circumstances which we might, or might not, be able to fight against" (Ninth group session, Carer 18). As a result, "we wanted and were enthusiastic to see if this group could bring about changes in our circumstances so that we could cope with our caring situations more positively" (Interview, Carer 6). However, as observed during the last three sessions, this feeling of empowerment had not yet been fully developed in these three family carers. This was illustrated by what one of them said:

> "I feel my group members are really keen for me to change my life. It is important for me to start practising the caring skills I learned from them and do something for my family. I have to put more effort into changing the negative feelings towards my son and start supporting him to face his illness. Even though I have been slow to catch up with the group in developing my caregiving skills, I feel more confident in being able to achieve this from now on..." (10th group session, Carer 16, paragraph 83)

The other four carers pointed out in the later group sessions that they "sometimes felt powerless when confronted by difficult situations that appeared impossible to change" but they learned to "overcome by various means, suggested by their group members, the negative feelings of guilt and hopelessness, that resulted from these unresolved problems" (Carer 17). For example, by using positive thinking and self-talk, or discussing with a close relative or friend the use of possible alternatives. Nevertheless, the feeling of empowerment gradually became more established in the group and strengthened their resistance against feelings of despair and the urge to relinquish and surrender their caregiving role, to the extent that, with increasing self-confidence and empathy, they were able to take action for themselves

and on behalf of other group members and their family members. From their comments in the interview, they were able to realise that the development of empowerment and competence in caregiving "took time to mature and become well established in our group" (Carer 11) and "required adequate on-going support from other members, even after the 12 group sessions" (Carer 15). This feeling of empowerment among the family carers and its positive effect to the development of the group, were found to be beneficial and fundamental to the adoption of their caregiving role by the carers and, thus, in working out this effective support group.

Inhibitory factors influencing group development and its success

The final component within the second theme that emerged from the interview and group session data concerned the positive and negative characteristics of the support group and was the major inhibitory factors or barriers undermining the development of the group and its success, as observed by the group participants. The first inhibitory factor identified from the data, was the irregular or low attendance by some group participants (i.e. those who attended less than six of the 12 group sessions). More than 10 group participants said it was unacceptable that attendance by a few members was unstable. They thought that "it was an excuse and often caused difficulty when it came to work out the membership of an effective support group" (Carer 15), like the one in this study. This behaviour was also felt to "create great problems over group cohesiveness and commitment, and made it seem more like the open membership of a social group" due to the high turnover and the presence of newcomers or "unfamiliar people" in most of the group meetings.

Despite the average high attendance and culture of closeness within the majority of the group membership, there were four carers whose behaviour much affected the group's functions and activities, due to their low level of contact with other group members and their irregular attendance. Some of these difficulties and concerns were raised in the interviews and group sessions, by 13 of the other members, including: "being less able to build trusting relationships or intimate social climate with a few members" (Interview, Carer 12), "lower continuity of care for mutual concerns" and, as the consequence of this, "lower level of achievement of personal goals and contracts" (Interview, Carer 11) and "fewer changes in behaviour and coping skills for caregiving than was desirable" (Seventh session, Carer 2).

Eight of these 13 carers, therefore, raised the possibility of encouraging regular attendance of group members and suggested this could be done by: "introducing more flexibility in the time of the group meetings" (Sixth group session, Carer 12), and "increasing opportunities for informal contacts outside group and the facilitator, as well as some enthusiastic group members, encouraging group participation" (Interview, Carer 2). Others suggested "more practical help and appropriate referrals to family support services, such as respite care if needed" (Interview, Carer 11), or "early intervention in cases where personal difficulties or lack of motivation affected those who failed to attend one or two group sessions, with home visits or telephone contacts by their 'best friends' in the group" (Fifth group session, Carer 18).

Another inhibitory factor in the development of the group suggested by 12 of the 20 carers, was the negative and high pressure put on acceptance of personal values, beliefs and behaviour in caregiving, by a few experienced and dominant members. For example, on several occasions, one dominant middle-aged carer tried to convince a young carer that he was responsible for his wife's mental illness, by saying to him:

> "We think that your family has great problems with communication and relationships. From what you said, your family's attitude towards the patient's behaviour was too demanding and negative. So, we maintain that this could be the reason why your wife developed the illness." (Fifth group session, Carer 30, paragraph 66)

Another dominant male member even tried to impose a 'stigmatised' identity on another group member, with criticisms and negative remarks such as "if somebody here lives with a 'crazy' family, we can't expect very much improvement or many significant changes from them" and "living in such family, you will never have any success" (Sixth and seventh group sessions, Carer 27). Three eloquent and less articulate carers suggested in the interview that the dominant and forceful members in the support group were "discouraging and critical" and that "more positive and balanced views about carers' own and family situations should be discussed within the group, with more guidance and reinforcement from the experienced carers and facilitator, being given well before other group members accepted the stigmatised identity and false beliefs" (Interview, Carer 14, paragraph 102).

The final inhibitory factors militating against the development of the support group and identified from the interview and group session data, was the forceful expression of some intense and negative feelings and conflicts aroused in the group. Five of the 20 carers were of the opinion that these intense and negative feelings

expressed by a few group participants during the first few group sessions, could overwhelm some of the other members if they were having very painful struggles with their family at the time. This was likely to happen if the patient had been exhibiting very annoying behaviour recently, or if the carer had just begun to take up the caregiving role, and was having minimal help from other family members and health professionals. In the third group session, one carer suddenly started crying loudly when another group participants talked about some negative feelings they were experiencing towards their patient in a very difficult family situation. The weeping carer admitted, after the group meeting, that admitted, after the group meeting, that she was having a very stressful time caring for her relative and any strong stimulation from people or the environment, could trigger an emotional outburst such as crying, being aggressive or screaming out. Fortunately, her adverse emotional reaction can be resolved with "the advice and reassurance immediately provided by my closest group-mates and the group facilitator" (Carer 17). Ten carers in the interview suggested that it would be better to share very intense and negative emotions about family situations in the later group stages, so that they "could establish adequate social support to each other before facing these painful experiences" (Interview, Carer 10, paragraph 70).

Eleven of the 38 carers in the later group sessions emphasised that the support group should pay more attention, as one father carer said, to "some positive, concrete support and demonstrations of effective coping methods, instead of investing such intense emotions, beliefs and values in past family events" (Ninth group session, Carer 7). One of them explained in the interview that: "the preference for practical help and actions rather than the open communication of emotions and ideas and values was common among Chinese people like us" (Interview, Carer 11). Five highly committed and expressive carers also suggested in the eighth group session, that it was better to focus on the group's collective efforts to "provide more practical and information support because these might convey to them that their family situation was neither helpless nor hopeless" (Interview, Carer 10).

Despite intense anger and other negative emotions such as aggression and hostility to other group members not being accepted by them, most of the carers did not know how to manage such strong emotions during the group meetings. The group facilitator and informal peer leader both played an important role in controlling the situation by various means, such as calling a time break to allow emotions to settle and

separating from the group for a while, as 'time-out' the one who displayed the strong emotion or temper tantrum.

8.4.3 Theme 3: Effects of autonomous group structure and the external support

In addition to the first two themes concerning factors that were apparent at both individual and group level, the third main theme that emerged was the importance of the structure of, and the external support for, the group programme. Both the internal structure of the support group and the quality of the external support environment had an important influence on the group's functioning and development. This theme consists of three key components including: the impact of a non-hierarchical and autonomous structure, the degree of professional involvement and support to the group, and the importance of informal support from family members, close friends and other people outside the group. The family carers considered all three components to be crucially helpful to the development of the group and, to the benefits derived from participating in the group itself. These three components are described as below.

Impact of a non-hierarchical and autonomous structure

This relatively small mutual support group decided not to adopt the formal hierarchy that is often found in large self-help organisation of 100 members or more and, instead, to adopt a more democratic style of administration. Within the support network inside the group, everybody was regarded as an equal member of the group, including the facilitator, who had no formal position or duty allocation. The fact that the support group was small in size, might have contributed to its autonomic social structure and energetic membership and, as 10 carers suggested in the interviews, "a greater sense of belonging and self-control" (Carer 4), together with "a stable attendance and intimate interpersonal relationships between participants" (Carer 10).

More than two-thirds of the 38 carers during the group sessions provided positive feedback about the dynamic, one-level structure and organisation of the group. They also commented on the need to establish informal roles for some of the more confident and trusted group members, regarding group maintenance and coordination. From the group session data, one example of their positive feedback came from a young male carer who said, concerning group maintenance and coordination:

> "I enjoyed the social structure of our group where all participants were considered to be of the same level and status, which meant that we felt more comfortable and free to talk about our own concerns and discuss our ideas and situations directly and openly…

> The group only discussed main topics in each session and we could change these if we wanted to. It was very important for me that I was able to take part in deciding what the group would talk about." (10th group session, Carer 3, paragraph 39)

In addition, as with the other seven carers, one of the novice carers made a constructive suggestion for the further improvement of the group's coordination:

> "I like the simple structure of the group, with no-one having any formal duty or responsibility. But sometimes, when I wanted to contact other group members on days between the group meetings, I didn't know how to make contact with them. In addition to the group facilitator, I think a few more of the (peer) coordinators or contact people in the group should keep us in contact with each other between group meetings." (Interview, Carer 17, paragraph 44)

This extract highlights the need for the group facilitator and peer leaders to do more to coordinator work and follow-up between group meetings, in order to maintain contact and communication amongst group participants and, especially between those who are in urgent need of practical aid and psychological support.

Importance of professional involvement and support

The perception about professional involvement and support for carers was another major component within this main theme, mainly identified from the interview data. The support group was run as an adjunct to the existing local mental health services, using their aids and facilities and so when speakers were needed for some of the group meetings, presentations by different mental health professionals were welcomed. Two-thirds of the 20 interviewees thought that by participating in these group meetings, the health professionals had been able to develop a closer acquaintance with the carers in the group and, equally important, the carers were able to become better acquainted with the professionals, so that they "felt comfortable about calling on them when needed" (Carer 5). The facilitator and the group's experienced carers were identified as the appropriate people to ask in the first instance, in the event that assistance from the appropriate services or from the health care system was required, especially when the need was urgent.

Fifteen carers (interviewees) indicated that the availability of these links at different levels were very important for meeting their individual psychosocial needs such as family and patient counselling by a clinical psychologist. This was illustrated by one female carer, who said in the interview:

> "Links with different professionals are important if we need individual psychosocial support, such as non-routine psychiatric or psychological consultations at the outpatient clinic, when we need additional patient care support during social and

> recreational activities... for skills training for patients using day services, or if we need telephone consultation and home visits by community psychiatric nurses." (Interview, Carer 8, paragraph 80)

Despite an increased awareness by the 15 carers of the family support services that were available in the local mental health care system, as found in the interview and group session data, the support group participants reported a significant reduction of their expressed needs for these services over the follow-up period (see Section 7.4.5 in Chapter 7). In addition, demands for use of these services by all the group participants decreased slightly and were not at the same level as the demand by the carers who received the routine psychiatric care only (control group). The mutual support group appeared not only to provide more knowledge about the available community resources for the carers and their families but also to help them understand the appropriate use of these services to meet their individual family needs.

Opinions about the level of involvement and nature of the partnership between health professionals and carers varied among the carers in the mutual support group. Eleven of the 20 carers interviewed would prefer a closely linked partnership with the health professionals at the outpatient clinics and in other agencies of psychiatric care, in addition to their participation in the support group. These 11 carers were those who showed mild or significant improvements in their psychosocial health conditions over the follow-up period. The carers who were interviewed and five of the others from the group sessions, suggested that the main reasons for such links with professionals outside the group included: (a) gaining additional psychosocial support and practical aid from the available community resources for patient care; (b) receiving respite care when needed; (c) seeking ad hoc advice and referrals for crisis intervention; and (d) obtaining up-to-date information about psychiatric care, particularly about new treatments and medication.

Five family carers in the support group expressed only limited interest in establishing a partnership with other health professionals involved in taking care of their mentally ill relatives. In the interview, three of them told other group members about incidents of poor communication with a few of the clinic staff, when they were accompanying patients who were attending psychiatric consultations and, in the interview, they reasoned that, "because of this, we would not be able to trust the staff as they were unsympathetic and disrespectful to us" (Carer 7). In spite of their bad experiences, they said they would like to have the opportunity of contacting specific professionals and services when the need arose, otherwise, they felt the support group could meet most of their needs for information and social support. The

five carers also said that participating in the support group had given them a feeling of self-respect, "as we had a role to play in making a positive contribution to the other group members and even to the whole mental health system" (Interview, Carer 7).

Support from family members and people outside group

The final component of the support to the group participants was the support that was available from their family members and other people such as close relatives and friends, within their social network. This support (particular from family members) was seen by 11 carers as being of equal importance as the support obtained from health professionals, (although they preferred more professional support, as described above). They said, in the interview, that they had learned from the support group that their family members and other close relatives should be seen as their primary source of immediate physical and emotional support while they were practicing their newly learned caregiving skills. The perceived importance of support from family members was in line with the scores for their family-related outcomes over the one-year follow-up period. In this, the support group participants who perceived themselves as having adequate support from family members and close relatives, indicated a greater improvement in their family burden and functioning scores than those with a lower amount of, and satisfaction with, the support they had received from their families and wider social network. The case for support from family members, strengthened by participation in the group, is illustrated by what one mother carer said:

> "The group emphasised the importance of having someone present at home to support my provision of care to my daughter (patient). As I shared my feelings and need for their help, with my husband and son, they were able to learn about my difficulties in caring for my daughter and understand that the whole family and to be involved. They could also see how the things I had learned from the support group were having a measure of success and they were able to understand what I was doing… no matter whether the problem can be solved or not, or how much I can be capable of doing." (Interview, Carer 1, paragraph 51)

The support of other people in their social network, such as close relatives and friends, appeared to vary according to the number of people available to the carers and their relationships with them. In general, from the interview data, the greater the number of friends available and the closer their relationship with the carers, the better and more satisfactory the social support the carers perceived themselves to have. It is also interesting to note that, for some personal issues, five of the 20 carers (interviewees) admitted that they were sometimes more willing to talk with their close friends or peers (and the group members) than with their family members. This was particularly the case when the relationship with their family members, had been affected by the family's anger and guilt towards the patient. When this

happened, there were also difficulties in communication with the older family members. A few reasons for this were suggested during their interview, including "being afraid of making our relationship worse" (Carer 4), "concern about respect for the elders" (Carer 10), and "there was more objectivity in discussing these issues with people outside" (Carer 16).

Finally, it is interesting to note more than half of the family carers recognised the importance of having a good relationship with somebody outside their family, to help them cope with the stresses of their caregiving. Although there were limited data from the group sessions on this understanding, the comment made by a male carer in the ninth group session was typical of others. He said:

> "I can see the importance of having somebody outside the support group to provide help and psychological support for my caregiving. My siblings and a few close friends were able to offer me immediate help whenever I needed it, and so it was not necessary for me to wait until the next group meeting to receive help from our group members. With the assistance and support from my friends, I was able to put into practice what I learned from the group, … I think this social relationship has been very positive and it ahs given me extra strength and warmth when caring for my family, as well as when I am caring for my patient." (Ninth group session, Carer 10, paragraph 28)

8.4.4 Summary

In summary, three main themes were identified as perceived by the carers as major benefits and therapeutic components of the mutual support group in this study. The first was for carers to look at their own individual situations and the extent to which they needed to change their view of the caring role, their perception of their patient's illness and the way they were coping with it. The second was to look at the positive and negative characteristics of the group and how they interacted with each other. The third theme was to look at the structure of the group and at their own family and social environment and the degree to which all these were supportive of them. Within these three themes, the results of the interview data were mostly supported by the data that had been gathered during the group sessions.

8.5 FOUR THERAPEUTIC MECHANISMS OF THE MUTUAL SUPPORT GROUP

The analysis of the data from the interviews and the tape-recorded group sessions elicited some important themes that were seen by the family carers as influencing the group process and benefiting individual carers, their families and the

group, as well as benefiting the group development. Four therapeutic mechanisms were then identified by bringing together these themes that had influenced the group development and contributed to the perceived benefits and success of the support group in this study. These four mechanisms were:

M1: Reconstructing a new positive self-image (role identity) in relation to caregiving (referred to Section 8.4.1);

M2: Establishing and focusing on clear, realistic common goals and tasks within group (referred to Section 8.4.2);

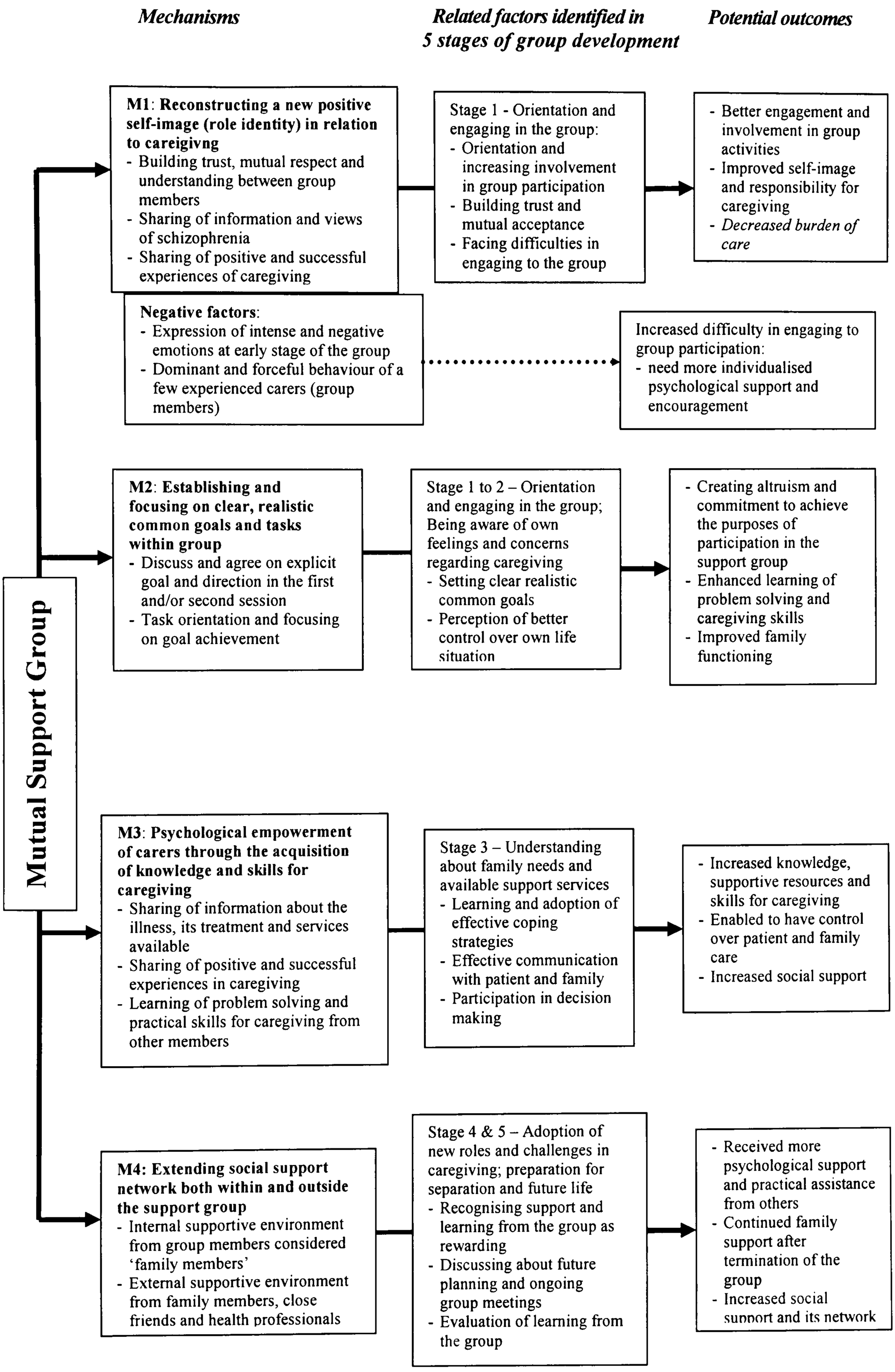
M3: Psychological empowerment of carers through the acquisition of knowledge and skills for caregiving (referred to Section 8.4.2);

M4: Extending social support network both within and outside the group (referred to Section 8.4.3).

The four mechanisms and their key elements are depicted in Figure 8.1. The flow diagram also presents the stages of group development associated with and the potential outcomes achieved by each mechanism. Some of these potential outcomes were demonstrated by the findings of the RCT. These included: decreased family burden might be contributed by reconstructing a new positive self-image for caregiving (M1); increased perceived social support might be resulted from psychological empowerment of carers through the acquisition of knowledge and skills for caregiving (M3) and extending social support network both within and outside the mutual support group (M4); and improved family functioning might be contributed by establishing and focusing on clear, realistic common goals and tasks within the group (M2). The four therapeutic mechanisms, indicated in Figure 8.1, will be discussed in detail in Chapter 9, along with other research and literature on mutual support groups.

In addition, one major hindrance to the success of the support group was also identified within one of the four mechanisms. The expression of intensive and negative emotions at early stage of the group and the presence of dominant and forceful behaviour of a few experienced carers might be negatively affected some family carers' reconstruction of their positive identity (M1), and increased their difficulty in engaging to group participation. These family carers might need individualised psychological support and encouragement by peer members and group facilitator to have better engagement in the support group.

Figure 8.1 Four therapeutic mechanisms of the mutual support group



CHAPTER 9 DISCUSSION OF FINDINGS ON THE EFFECTIVENESS OF MUTUAL SUPPORT GROUP AND ITS THERAPEUTIC MECHANISMS

9.1 INTRODUCTION

This chapter discusses the effectiveness of the mutual support group programme used in this clinical trial (see Section 9.2) and considers this in the light of previous research, particularly the studies described in Chapters 2 and 3. It also examines the four therapeutic mechanisms of the support group (in Section 9.3) that emerged from the interview and group session data in Chapter 8 and, in the light of previous research, draws together these mechanisms and the findings on the health outcomes of the support group.

9.2 EFFECTIVENESS OF MUTUAL SUPPORT GROUP FOR FAMILIES OF PEOPLE WITH SCHIZOPHRENIA

The client-led mutual support group intervention for families of patients with schizophrenia used in this study, demonstrated a significant overall positive effect in the psychosocial conditions of family carers and their patients over a 12-month follow-up period. The results of the RCT demonstrated that the mutual support group intervention could produce statistically significant improvements in most of the psychosocial measures of both the family carers and their patients, particularly when it came to family burden and functioning, utilisation of family services, patient functioning, and length of patients' re-hospitalisation. The improvements in the support group participants were statistically and significantly greater over the 12-month follow-up period than those who had received only the usual psychiatric outpatient care. Between half and three-quarters of the support group participants also showed clinically significant changes in family burden and functioning and patient functioning at the final post-test (12-months after intervention). These significant positive outcomes of the support group are discussed as follows:

9.2.1 Improvement in family burden and overall functioning

The findings of this RCT demonstrated that the family carers in the mutual support group had experienced a significant reduction in the burden of family caregiving as well as a significant improvement in family functioning over the 12-month follow-up period,

when compared to the control group who had received only the usual outpatient care. These findings support the view that there were statistically significant differences in families' perceived burden of care and functioning (also, increased social support described in Section 9.2.2) between the mutual support and control groups over the follow-up period and hence the first and second null hypotheses (i.e. H1 and H2 in Section 6.2.2) of this RCT were rejected. The effect sizes of the two outcomes were large (partial eta squared= 0.24 for family burden and 0.22 for family functioning between groups, and 0.17 and 0.32, respectively, for group by time interaction), as suggested by Cohen (1992).

These findings were in line with the verbal feedback given by the participants in the mutual support group during interviews and group sessions. As mentioned in Section 8.4.1 of Chapter 8, during group participation, family carers in the support group spoke about the positive changes they had experienced in their sense of personal identity in relation to their caregiving and also in their perception of the mental illness. They felt less guilty and frustrated than previously and reported a heightened understanding of their patient relative's illness and condition. More than half of them also indicated, during the group sessions, that they were able to relieve their caregiving burden by 'letting go' useless and ineffective attempts to make their patient care methods conform to strict pre-conceived ideas and learned, instead, to redefine the patients' problems and find more flexible and positive ways of coping with them. They learned to avoid viewing themselves as "victims" and, instead of feeling resentful, they learned to view their mentally ill relative with compassion.

There is evidence that the burden and psychological distress of caregiving can impair family carers' ability to cope with and provide care for relatives with schizophrenia (Sisk, 2000; Solomon & Draine, 1995). This study shows that a mutual support group can resolve or lessen this sense of burden and distress. It may also help family carers identify problems with their caregiving and use problem-solving techniques to resolve them. It may therefore enhance family carers' adaptation to the caregiving role and tasks and promote their psychological well-being. Nevertheless, it is interesting to find that the physical health of the family carers who had participated in the mutual support group was no difference from the health of those carers whose patients had received only the usual outpatient care. This can be explained by the fact that, although patients with

schizophrenia and other severe mental illnesses may not require as much physical care as patients with other chronic physical illnesses, the psychotic symptoms often result in disturbances in the patient's psychological and social life (Ohaeri, 2003). Although the effect of the intervention on family carers' physical health was not significantly different between the mutual support and standard care groups, the findings support those of other studies which showed that mutual support groups can provide much needed information and emotional support and, sometimes, practical assistance for carers, and can confirm for them the importance and responsibility of their family caregiving role (Budd & Hughes, 1997; Kurtz, 1997).

It is also important and interesting to note that the mutual support group participants reported, during the follow-up period, that they had experienced significant improvements in all aspects of their family functioning, including their capacity to solve problems, their ability to communicate, their role performance, their involvement with and patience in responding to their patients and also their ability to control the patients behaviour and general functioning. It is well recognised that one major negative effect for families caring for patients with severe mental illness is the interference and disruption caused to family relationships and the overall functioning of the family (Mueser & Glynn, 1999). This is exacerbated by false beliefs concerning what carers perceive to be the social stigma towards mental illness in Chinese and Asian countries (Meredith et al., 1994). Therefore, maintaining and improving normal family functioning and decreasing the burden of caregiving on the family, are important goals for family support and care to achieve, so that family carers and other family members can remain involved with their loved ones, while maintaining their own psychological and social well-being. The mutual support group used in this study was successful in demonstrating the efficacy of this mental health protection and promotion.

The mutual support group's positive effect on different aspects of family functioning is underlined by the results of analysis of the interview and group session data in Chapter 8. Sections 8.3.3 and 8.4.1 show how the mutual support group was able to encourage positive changes in the family carers' understanding of schizophrenia and in their caregiving skills. Family carers learned effective ways of communicating with their patients, and adopted the new coping methods learned from other members in the support

group, who shared their own skills for effective caregiving practice. Family members' perceptions of the benefits of family support groups were consistent with similar findings in studies conducted in Australia (Winefield et al., 1998), Belgium (Lemmens et al., 2003) and the USA (Citron et al., 1999), suggesting that group participation enabled these families to help themselves. Family carers' ability to help themselves grew as they received knowledge about the care required by their relative with schizophrenia and practiced the effective skills that they learned from other group members who used them in their own family situations (see "informational support and feeling of empowerment' in Section 8.4.2). In addition, after the family carers had attended the support group for six to seven sessions, many of them reported positive and happy interactions and activities with the patients. After discussion with other group members, they were able to establish their own home management strategies with, for example, more effective financial and budgeting strategies and the maintenance of a harmonious family environment and relationships (see Section 8.3.3).

The improvement in all aspects of family functioning shown in this study is a positive and significant finding and supports the introduction of mutual support groups as an effective alternative model of family intervention for patients with schizophrenia, particularly in Chinese populations. Evidence from previous studies suggests that mutual support groups can improve family functioning for carers of people with schizophrenia and other chronic mental illnesses through two mechanisms: (1) increased social support, resulting in an increased sense of control over interpersonal skills and other aspects of family life; and (2) role modelling positive family interactions by other group members (family carers) in similar life situations (Citron et al, 1999; Heller et al., 1997). Powell (1994) in his review of self-help group research, suggested that mutual support groups can encourage and provide different types of social support to family carers (and patients or both parties) adequately, including informational, emotional, interpersonal, and instrumental supports, which are very important for maintenance of normal family activities, effective communication, and family relationships. Through the sharing of both successful and futile experiences in caregiving among group participants, family carers are able to better understand the importance of inter-dependence and mutual support between family members and how these can enable them to exercise control over family situations

and manage patient behaviour (Powell, 1994). In addition, they are able to learn how to enhance recognition by other family members of their role and responsibility and of their physical and emotional involvement in the care they are giving (Schiff & Bargal, 2000). These findings suggest that mutual support groups produce benefits not only for the group participants' psychosocial well-being, but also, indirectly, for other family members health and behaviour.

Moreover, a striking finding of this study is that the effect of the mutual support group on different aspects of family burden and functioning was considerable when defined by Cohen's (1992) criterion and this significant positive effect was continuous and substantive over the one-year follow-up period of this study. The post-intervention family burden and functioning scores in the support group were significantly different from those of the control group and the two sets of scores generated a very satisfactory power score for the study, (0.95 for family burden and 0.97 for family functioning scores), which was calculated using the Power Analysis and Sample Size (PASS) version 6.0 for Windows (Hintz, 1996). As few known studies evaluate the effect of mutual support groups on patients with schizophrenia on family burden and other family-related health outcomes in Western or Asian countries, (see the literature review in Chapter 3), these positive findings provide more support for the use of mutual support groups as an integral part of family-oriented mental health care for people with schizophrenia. These findings also demonstrate that the efforts by psychiatric/mental health nurses and other health professionals, to establish and facilitate mutual support groups for family carers of people with schizophrenia, can lead to major benefits for family carers and indirect benefits for the family, as well as for their patients. The positive result for the entire family may be that following intervention they enjoy a more supportive and harmonious family environment (Heller et al., 1997).

Another important finding of this study was the reduction in incidents of family conflict over the 12-month follow-up period and this outcome variable was found to correlate statistically with family burden and functioning (see Section 7.3 and Appendix 13). In addition, the mutual support group demonstrated a continuous, although small, reduction in family conflicts over time, whilst the standard care group indicated a consistent slight increase only over the follow-up period. These findings reveal that the

mutual support group may be effective in improving the communication and relationship between family members, particularly between family carers and their patients; and this improvement can have positive effects on overall functioning of family carers as well as the entire family.

Family conflicts can often reflect the relational problems between family members, where the involved parties are unable to reconcile their different views and opinions on family situations and affairs. There is consistent evidence that persistent and frequent conflicts have a detrimental psychological effect on all family members, such as low self-esteem, anxiety and depression (Chen & Davenport, 2005; Lee & Liu, 2001). These negative psychological effects are particularly seen among Chinese, Japanese and other Asian families, in which close and intimate parent-child and inter-generational relationships are largely intended to avoid distress and disharmony, while promoting inter-dependence and emotional closeness between family members (Lee & Liu, 2001; Meredith, 1994). Lee and Liu also found that Chinese Americans had higher levels of familism and family conflicts than did the Hispanic people. By contrast, in the USA and the UK, parental and inter-generational care for families is largely intended to provide a secure base that promotes the relative's self exploration, as well as encouraging the assertion of their personal desires, independence and autonomous efforts to satisfy their own needs (Rothbaum et al., 2002).

Chinese family carers, such as those in this study, may appear emotionally over-involved and too anxious and demanding when providing care for their sick relative and other family members, especially as this appears to lead to an increased frequency of quarrels and conflicts among family members, when carers cannot cope with patient and family care. Mutual support groups can help in resolving these family conflicts, through family members learning direct coping strategies from other group members. These include strategies such as active planning and the practice of family conflict management, seeking support from relatives and professionals and maintaining a positive hope for patient recovery (Chou et al., 2002; Citron et al., 1999). Appropriate use of these direct coping strategies can replace thought suppression (for example, by use of self-distraction, denial and other forms of indirect coping), which can, inadvertently, maintain or exacerbate the feelings of distress, rather than ameliorating them (Lee & Liu,

2001) and use, instead, active problem-solving approaches to managing family conflicts. Section 9.2.5 presents a detailed discussion about the relevance, from a cultural perspective, of mutual support groups to Chinese families caring for a relative with schizophrenia. This positive finding suggests that more research is necessary to investigate the potential relationships between family conflicts, psychological distress and coping strategies among family carers in different cultural groups.

9.2.2 Increase of perceived social support

In this study, social support was operationally defined as "perceived psychological and material resources for family carers, derived from social interaction with others in their social network, leading to an improvement in their ability to cope with the mental illness and its care." Under this definition, the adequacy of social support should take account of at least of two aspects: (1) the number of people that family carers perceive to have obtained support from and (2) the level of satisfaction of family carers with the psychological or material resources received from the supporting persons, such as relatives and close friends. Sociological and health researchers have suggested that the adequacy of social support should be measured from the perspective of the recipients (such as the family carers in this study) and not from the point of view of the supporting persons or health professionals (Coriell & Cohen, 1995; Wills & Fegan, 2001). The results of this RCT in relation to social support (refer to Section 7.4.3) are not surprising, but are important because they show both these aspects of social support to be significantly improved within the intervention group, when compared with the control (standard care) group. Despite there being a significant but small effect size between groups (partial eta squared= 0.06) and within groups over time (eta squared= 0.05), the repeated measures MANOVA results indicated that the average number of support persons available to the family carers in the mutual support group consistently and significantly increased from 3.0 (SD= 0.7) at baseline measurement, to 4.3 (SD= 0.7) at 12 months after intervention, whilst the standard care group indicated a consistent decrease in the number of support persons (3.0 to 2.5) over the same period.

In addition, the ANOVA results indicated that the level of satisfaction with the social support that was available in the mutual support group also consistently and

significantly increased from 3.1 (SD= 0.6) to 4.2 (SD= 0.7) during the study period but, on the other hand, satisfaction in the standard care group decreased consistently from 3.1 to 2.3. The significantly positive findings of perceived social support are consistent with the theoretical concepts of social support and mutual support groups, and their roles in mental health and intervention with people who have severe mental disorders described in Chapter 3 (Sections 3.2 to 3.5).

In sum, these findings, together with the positive effect on family functioning discussed in Section 9.2.1, demonstrate that there were significant differences in family psychosocial outcomes (i.e. family functioning and perceived social support) between the families who participated in the mutual support group and the controls who received only the usual outpatient service, over the follow-up period. Thus, the second null hypothesis of this study (i.e. H2 in Section 6.2.2) was rejected.

The functional dimensions of social support are highlighted in the group work literature and focus on three types of resources: instrumental support (i.e. the provision of material aids and practical help with daily tasks), informational support (i.e. the provision of appropriate information and advice in dealing with the illness and its care) and emotional support (i.e. the expression of empathy, caring and trust) (Bogat, Sullivan & Grober, 1993). They are also the key components of the mutual support group in this study and of similar programmes reported in previous studies (Winefield & Harvey, 1995; Heller et al., 1997; Chou et al., 2002). The presence of these functional dimensions and their importance within mutual support was reflected in the interview and group session data. For example, in Section 8.4.2, most of the family carers in the support group in this study demonstrated a satisfactory unity and coherence among themselves by showing their commitment to the group, and friendship for one another. Between the group meetings, some of the mutual support group members assisted carers with household chores and management of family affairs. Family carers were also struck by the friendliness and practical advice provided by some of the group members. As described in Section 8.4.1, the group participants indicated that they had gained a lot of experiential knowledge about caring for their relative with schizophrenia from others who had lived through and resolved similar problems in their own caring role and the participants felt that they would not have been able to obtain this information from the expertise of

health professionals alone. Their experiential learning began as they listened to the personal stories of group members within the supportive group environment. More than half (ten) of the interviewees suggested that this way of sharing was useful in "building mutual trust" and helped to "demonstrate group members' concern and care for each other."

In addition to any perceptions the family carers had of the availability of social support, they felt the receipt of verbal and practical support during difficult periods of caregiving could play a role in reducing the demands of caring and the resultant stress. This is consistent with the findings of previous studies which suggest that mutual support groups might alleviate the impact of stress by identifying alternative ways of solving problems through group discussion, by providing practical assistance to solve the problem, by reducing the perceived importance of the problem, or by providing a distraction from the problem (Cohen et al., 2000; Wituk et al., 2000).

Cohen (2004) suggested that, in addition, constructive advice provided by other supportive members in a therapeutic group and their companionship during various kinds of social activities during and outside group meetings, might encourage more healthy behaviour by family carers, such as the practice of greater self care, undertaking more recreational activities, better nutrition, and more rest. In this study, as described in Section 8.4.1, more than two-thirds (n= 13) of the interviewees who participated in the support group said that, through their group membership, they had seen the possibility of a more meaningful life of their own, even though they knew they would have to continue to live with unresolved difficulties. This glimpse of better times ahead helped them re-establish or build new, healthier behaviour in their daily life.

Mutual support groups can help counteract some of the negative effects of mental illness on social relationships and the integration of families of patients with schizophrenia, who are often socially isolated due to frequent or prolonged patients' re-hospitalisations, their persistent psychiatric symptoms and the social stigma attached to the illness (Horwitz & Reinhard, 1992; Lefley, 1996). The support group itself can be considered as an informal family support network and group members are sometimes treated like intimate relatives or close friends, as indicated by the group participants in this study (see Section 8.4.2). The consistent increase in the number of support persons among the group

participants over the follow-up period also confirms that mutual support groups, like the one used in this study, can help family carers of patients with schizophrenia to re-establish or expand their social support network. The stress buffering model (Cohen, 2004) asserts that such improvement in social relationships and connections can eliminate or reduce the effects of stressful caregiving by providing group members with the psychological and material resources they need to cope with their caregiving difficulties and by promoting less threatening interpretations of their own adverse events.

Recent literature also suggests that a critical factor in explaining the benefits of social support as a buffer against stress is the perception that others will be providing appropriate aid or support. This may have the effect of bolstering family carers' confidence in their own ability to cope with the demands, thus changing their appraisal of the situation in a more positive and hopeful direction and limiting the likelihood of maladaptive responses, such as social withdrawal (Cohen, 2004; Lakey & Cohen, 2000). This stress buffering function fits well with the main purpose of mutual support groups, which is to provide reciprocal practical help and emotional ventilation and support for those family carers who are experiencing stressful family events and feelings of helplessness. Both the quantitative and qualitative results of this study reflect the stress-moderating effects of social support on family carers of people with schizophrenia. It was suggested by Caprara and Steca (2005) that this was due to reframing the concept of mental illness and the experiences of social stigma and then encouraging an increase of self-efficacy for coping with the stress in caregiving, in the later group stage.

In addition, the findings in this study revealed that the number of support persons available to the family carers and their satisfaction with the support provided by their social support network, were both important and closely associated with a decrease in family burden and improved functioning for the family carer participants, as well as for their patients. This implies that a larger supportive social network (i.e. more support persons available) results in better social support. However, Langford et al. (1997) caution that large social support networks do not necessarily indicate larger amounts of support. Previous research by Gottlieb (1992) indicates that the quality, type and amount of social support received by family carers who are in need of support, are also important

determinants of the effectiveness of the support. Therefore, family carers' satisfaction with the perceived or actual support they receive requires evaluation by health professionals to identify the appropriateness of the intervention. Kouzis et al. (2000) suggested that the source of the support also plays a central role in perceived satisfaction of that support. If it is considered appropriate, then its potential value is increased, for example, by the advice and assurances given by carers with similar caregiving situations in the mutual support group used in this study.

Participation in a mutual support group would be expected to strengthen family carers' support systems and precipitate improvement in families' psychosocial problems, such as management of the patient's problematic symptoms as well as the carer's own emotional reactions to the restriction of his/her social activities, due to caregiving. Some studies also suggest some additional merits of social support, such as the maintenance of, or positive changes in personal identity and providing access to social contacts who are available for companionship and participation in various kinds of leisure activities (Cohen and Wills, 1985; Pierce et al., 1996). These functions were found to be present in the mutual support group in this study and were specifically mentioned by the group participants in the interviews and group sessions, for example: the perceived self-image (identity) transformation (see Section 8.4.1); group members' encouragement and companionship in social activities (see Section 8.4.2); and the professional involvement and support carers received outside group meetings (see Section 8.4.3). Such types of social support can provide a basis for determining whether the effectiveness of different kinds of support differs due to the nature of stressful events, or because of the characteristics of the family carer, or because of the patient suffering adversity (Cohen et al., 2000). The mutual support group used in this study was able to serve the purpose of providing different kinds of psychosocial support to the family carers as needed, while conferring with the carers about their specific problems and concerns in caregiving.

The main effect model (see Section 3.3.2) suggests that social integration can engender feelings of responsibility for others, resulting in feelings of positive self-worth and an increased motivation to take care of oneself (Cohen, 1988). Participation in a mutual support group can enhance the effect of social integration and, within the support group, concepts of the social roles and responsibilities shared amongst a group of people,

by helping to guide social interaction and by providing a common set of expectations about how people should act in different roles (Cacioppo et al., 2002). Wright (1998), in the Indianapolis Network Mental Health Study in the USA, also suggests that the most important benefit of social ties and greater connectedness with people who understand the caregiving situations is the increase in the carers' enthusiasm for improving their own psychosocial functioning so that they can cope better with the strains and demands involved in the long-term care of their sick relative. The findings of this study indicate that mutual support groups for families of patients with schizophrenia, which aim at increasing social connectedness and mutual help between group members sharing similar situations, are equipped to serve these mental health promotion purposes.

9.2.3 Effect on perceived need for and utilisation of family support services

The mutual support group tested in this study indicated a significantly greater reduction of need for family support services by family carers, over the 12-month follow-up period, than for the families under standard psychiatric outpatient care. This need reduction among the group participants can possibly be explained by: (1) fewer demands on community services due to significant improvements in their patients' and their own psychosocial health condition and functioning; (2) receipt of adequate practical aids and psychological support from the other group members, their family members and friends, and the health professionals; and (3) their enhanced capability to choose the services most appropriate to their family needs, as a result of learning from the experience of other group members.

These possible mechanisms are illustrated by the themes that emerged from the interview and group session data of some of the group participants. For example, in Section 8.4.1, most participants pointed out that support group participation helped them reframe their understanding of life problems and mental illness and to be happier about their caregiving role. Such a positive change in their view of their situation, contributed to their learning different ways, from the group, of coping more effectively with caregiving. A typical comment was: "I really enjoyed being in the group and learned to re-structure and resolve problems stemming from my care provision." (11th group session, Carer 3, paragraph 48). In addition, in Section 8.4.2, over two-thirds of the group participants

indicated that they assisted another member with household chores and family affairs outside the time of the group meeting. This tangible assistance and support was perceived by them to be more useful and important than some of the community services that they received. Most of the family carers emphasised that they considered the support group an inviting place to go (see 'Relational social climate' in Section 8.4.2), because they perceived that the group was realistic in helping them resolve their difficulties and helped to reduce their frustrations and other negative emotions. It is possible, therefore, that the support group helped to improve family carers' problem-solving skills, in addition to their knowledge about mental illness and their competence in handling the demands of caregiving. Thus, these families were less in need of family support services such as an information hotline and family counselling services, than those who did not receive the intervention. This hypothesis is supported by Heller et al. (1997) in their study of families of adults with severe mental illness in the US, who found that appropriate service utilisation can optimise the demands of client-centred mental health care and resources.

This finding is also consistent with previous findings by Gidron et al. (1990) and Leff (2000) who suggest that mutual support in a family group therapy can be a stress-reducing mediator for families in a psychosocial crisis, by showing empathy and sharing the feeling of being 'all in the same boat', in addition to the sharing of information and instrumental supports to meet families' health needs among group members. Moreover, previous studies of the effects of mutual support group interventions for Chinese families with a relative with mental illness have reported that, over a period of a few months, the support group is an effective vehicle for passing on practical advice and experience, along with information on the appropriate community services to meet family needs (Leung et al. 1993, Pearson & Ning 1997). The evidence from this study and previous studies suggests that mutual support groups and other follow-up care, if embedded in the usual community services, will enhance appropriate help-seeking behaviour and self-efficacy in caregiving, thereby ensuring more appropriate and optimal service utilisation.

It is also interesting to note that there was little variation in the average amount of community services that the family carers in the mutual support group received over the study period (M= 4.3, SD= 0.7 to M= 4.5, SD= 1.3) whereas the families receiving only

standard care indicated an increase of service utilisation from 4.0 (SD= 1.2) at baseline to 5.2 (SD= 1.1) at one week post-intervention and 5.0 (SD= 0.9) at six months post-intervention, although this dropped and returned to around their baseline level at 12-months after intervention (M= 4.0, SD= 0.8). Previous research indicates that the psychological and social support received by family members caring for a relative with schizophrenia or other mental illness and the community resources they can utilise to manage the internal and external strains as the result of the burden of care, can protect the family unit from major disruption and psychological distress during times of hardship and change (Saunders, 1999; Stein & Wemmerus, 2001).

Reducing families' demands for community services and teaching them more appropriate service utilisation to meet their relative's health needs may be another positive effect of the mutual support group. The consistently low utilisation of services by the group participants in this study seems to bear this out. In contrast, the families receiving routine psychiatric care demonstrated an unstable but higher demand for family support services. On the other hand, the greater reduction of service utilisation in the standard care group at 12 months after intervention, might be related to the increase in the patients' re-hospitalisation rate, from 8.6 (SD= 6.1) days/months at baseline to 12.6 (SD= 7.8) days/month at 12 months following the intervention. The families did not require so many of the services when their relatives with schizophrenia were re-hospitalised.

Despite moderate levels of family functioning, the families in this study reported lower levels of family support service utilisation at baseline, when compared with North American samples (Citron et al., 1999; Cook et al., 1999). This may be explained by the reluctance of Chinese people to reveal family matters to others, particularly to strangers, or to seek professional help, even when they are in most dire need (Fung & Ma 1997). Traditionally, Chinese people often prefer to seek help from relatives and close friends, whom they perceive as being better able to understand and accept their family situation and the difficulties involved in caring for a mentally ill relative (Pearson & Ning, 1997). This may also be one of the reasons why traditional family therapy may not be effective for Chinese families. Many of them find it difficult to establish trust with their therapist, whom they may consider an outsider or a 'stranger' to them. In addition, many family carers lack information about the types and appropriateness of services available for their

family situation. As identified from the interview and group session data, most family carers in the support group emphasised that they received useful and up-to-date information about appropriate health services from other group members.

9.2.4 Improvement in patients' mental and psychosocial condition

The mutual support group investigated in this study demonstrated statistically significant improvements in overall patient functioning and its five aspects, including personal care, interpersonal relationships, social acceptability, daily living activities and work skills, over 12-months after the intervention. However, patients in the standard care group showed little improvement or deterioration in their different aspects of functioning. Patients' improvements in overall functioning in the mutual support group demonstrated large effect sizes over the follow-up period (partial eta squared= 0.50 between groups and 0.21 for group by time interaction). This finding provides evidence that mutual support groups can be an effective alternative model of family intervention in helping families provide adequate and appropriate care for patients with schizophrenia. These findings are similar to the results of controlled trials of family intervention using other approaches of intervention, summarised in recent meta-analyses (for example, Pharoah et al., 2001 & Pilling et al., 2002). Pharoah et al. and Pilling et al.'s meta-analyses of studies involved over 2,000 patients with schizophrenia (from 1980 to 1999), in different countries such as the USA, the UK, and mainland China. However, most studies demonstrate that family intervention only has an effect on patient outcomes, including reducing patients' relapse and re-admissions and improving their medication compliance.

Physical function, one aspect (subscale) of patient functioning, showed only mild change in the mutual support and standard care groups over the follow-up period. This may be explained by the fact that the patients in the two groups did not indicate any notable problems or impairment in their physical abilities, including vision, hearing, speech, walking and use of legs, and use of hands and arms. With the possible range of scores from five to 25, the mean scores of this subscale were between 21.4 (SD= 1.4) and 23.3 (SD= 0.9) in the mutual support group and between 21.0 (SD= 1.4) and 22.1 (SD= 1.6) for those in standard care only, over the study period. Patients with schizophrenia generally do not present any serious side effects of antipsychotics such as dystonia and the

pseudo-parkinsonism effect nor does schizophrenia usually cause much disturbance to the sensory, motor or other physical functions, with the exception of catatonic schizophrenia, which is rarely found amongst patients with schizophrenia.

In addition, this study, consistent with findings of research studies in Western countries (Cook et al., 1999; Humphreys, 1997), also demonstrated a continuous significant decrease in the length of patients' psychiatric hospital stay for the mutual support group over the follow-up period, compared with the psychiatric hospital stay of the controls (standard care). Length of patients' re-hospitalisation following the intervention has been used in previous studies as an outcome indicator of an improvement or deterioration of a patient's mental condition, and a reduced or an additional cost for the mental health care system (Hogarty et al., 1997). Reduction of hospital stay for patients in the mutual support group, as found in this study, is consistent with increasing research evidence that indicates that participation in a mutual support group for families caring for a patient with chronic physical or mental illness, is strongly associated with improvements in the status of patients' general health (Zola, 1991) and their families' psychological adjustment (McCallion & Toseland, 1995).

These positive findings show that mutual support groups can improve the psychosocial functioning and mental state of patients with schizophrenia, who are being cared for by the family members participating in the group. While the symptom severity of the patients did not differ between the two groups, the participants in the mutual support group reported a mild reduction in the psychiatric symptoms (using the Brief Psychiatric Rating Scale, BPRS), compared with that of the patients in the standard care group. However, the BPRS might not be specific and sensitive enough for measuring the changes of positive and negative symptoms for schizophrenia. Other research instruments such as the Positive and Negative Syndrome Scale (Kay, Fizzbein & Opler, 1987) are considered superior for the accurate description of mental status of patients with schizophrenia. Despite showing non-significant changes in patients' psychiatric symptoms, the null hypothesis (H3), that there would be no significant difference in the patient functioning and the length of patients' re-hospitalisation between the mutual support and control group over the follow-up period, was rejected. The findings of this study are also consistent with the findings of previous studies for other severe mental illnesses, such as affective and

schizoaffective disorders (Norton et al., 1993; Dyck et al., 2002), which demonstrated that increased savings in health care costs and resources in family mutual support groups, relative to routine psychiatric care, may be largely due to shorter hospital stays and more appropriate use of mental health services.

It is encouraging that the findings of this study show that a mutual support group, which has neither been tested in controlled trials, nor has been reported in literature reviews or meta-analysis of family intervention for patients with schizophrenia, demonstrates similar (and even more) significant effects on patients' mental and psychosocial conditions, than other models of family intervention. The American Psychiatric Association (1997) and Schizophrenia Patient Outcomes Research Team (Lehman, Steinwachs & the Survey Co-investigators of the PORT project, 1998) recommended that patients who have on-going contact with their families, should be offered a family psychosocial intervention organised around the central theme of providing their family members with education about the illness, guidance and resources for patient care during crisis, and training in managing caregiving problems.

Even though the structure and technique of a mutual support group intervention are quite different from that of other approaches of family intervention, the mutual support group used in this study shared common content and focus with those of other approaches reported in previous studies (Pharoah et al., 2001; Thornicroft & Susser, 2001), including: (1) working in alliance with families who care for the person with schizophrenia to identify stressors associated with family dysfunction and patients' relapse; (2) enhancing problem anticipation and problem solving; (3) setting realistic expectations on patients' functioning and performance; (4) helping families improve their communication and relationship with patients; and (5) attaining desirable change in family members' behaviour and belief about the illness and its care. The mutual support group was similar in format and length of programme to some multiple-family group interventions for people with schizophrenia in the UK (for example, Leff et al., 1990) and the US (e.g. Schooler et al., 1997) and demonstrated a similar positive effect on patients' relapse over one-year follow-up. Whilst other studies of multiple-family group interventions have failed to find marked improvement in family functioning or psychological well-being, the mutual support group in this study provided positive effects on family burden and functioning.

These findings also support Cook et al.'s (1999) contention that a mutual support group can be an effective way for family carers to share common experiences and problems by providing a medium for reciprocal help and transmission of knowledge and skills of patient care, and thus improve patient's mental state and functioning in daily living. Nevertheless, patients' mental condition can also be affected by the use of medication and compliance. Despite medication compliance not being monitored, this study assessed the types and dosage of neuroleptic medications used by the patients and found that there were no significant differences between the types of medication and dosage within and between the mutual support and control groups, over the follow-up period. Similar practice of long-term use of antipsychotic medication (for example, more than one year), with low to moderate dosage, is found amongst patients with schizophrenia for stabilising psychiatric symptoms and allowing patients to be more receptive to other psychosocial interventions (Solomon, 2000).

Review of the interview and group session data showed that the group participants employed active and interactive help-seeking coping strategies (see Section 8.4.1 for participants' changes in perception of mental illness and coping ability), such as reading about and exploration of the problems encountered in caring for the patient, and discussions about ways of coping with caregiving situations. These coping strategies may also enhance the families' knowledge about the illness and their skills for caregiving. The family carers also obtained useful information support and psychological empowerment from participation in the support group (see Section 8.4.2) and this might also help them in their provision of patient care and, subsequently, might improve the patients' health condition.

Many family group programmes such as psycho-educational and cognitive-behavioural intervention approaches, include patients in most or all group meetings and consist of an education component and training in behavioural and problem-solving skills (Asen, 2002). The mutual support group used in this study did not include the patient in most of the group sessions. However, the effect of the group programme, when it did include the patients, was found to be significant and positive. The two group sessions which included the patient were: the second session consisting of discussion of the patients' illness, symptoms, behaviour and their effect on the family; and the sixth session

in which participants shared information about medication, management of the illness, and available mental health services for patients and families. It appears that these two sessions might be sufficient to provide patients with an insight into their illness and information about its treatment, and also about care in the home setting and its effect on family members. The other 10 group sessions were focused on the concerns of carers and their health needs in caregiving, in which the presence of patients might have made the carers feel uncomfortable, in particular, as suggested by Saunders (1999) and Wilson (1995), those aspects of caring behaviour which related to patients' problem behaviour or the carers' emotional reactions towards them. The influence of the presence of patients on the effectiveness of a family mutual support group, or family carers' perceptions of patient presence, could be an interesting and additional area of research for family group work.

9.2.5 A cultural perspective on the effects of a mutual support group on family carers

The family system is often considered to be an open system and an integral part of the community. Successful family adaptation to the mental illness requires family members to make adjustments to their roles and responsibilities within the system, in order to meet the needs of individual family members, as well as the family as a whole (McCubbin & McCubbin, 1993). Studies in the USA and amongst Chinese populations indicate that elders and parents of Asian and Hispanic heritage expect their family members to participate in their care, especially when they are sick, whereas Caucasian families are more likely to view living with their children as a sign of failure (Kawachi & Berkman, 2001). Many Chinese families, including those in Hong Kong, are willing to take care of their family member with schizophrenia at home but, due to financial pressures and problems in achieving social acceptance, they need to build a good social network and identify what appropriate community resources are available for providing respite care, and the best quality care for their ill relative (Chan & Yu, 2004). This study suggests that mutual support groups can assist in building an intimate social support network among the family carers and can also help them obtain up-to-date information on the availability of appropriate community resources for their patient care.

Hong Kong Chinese family carers, such as those in this study, have a strong sense

of kinship and cohesiveness with their extended families and hold traditional cultural beliefs of obligation, filial responsibility towards elders, and inter-dependent relationships (Tsu & Tseng, 1991). It is not unusual for family members in Asian and Latin American families to blame themselves for the ill health of other family members and for this sense of guilt to prevent them from living harmoniously with their disabled relative (Lee & Liu, 2001; Meredith et al., 1994). This study suggests that similar mechanisms may apply to Chinese families. In such circumstances, family carers may need information, emotional support and social empowerment from other people, such as other support group members and health professionals, before their anxiety and self-blame about their relative's mental illness can be overcome and their care needs met.

As with the findings from the interviews and group sessions in this study, previous studies of family caregiving (for example by Chou et al., 2002 and Winefield & Harvey, 1994), have suggested that strong friendship ties and mutual help between group participants provide an additional source of social support, companionship and help in maintaining hope when caring for people with severe mental illness. According to Chan and Rhind (1997), mutual support group interventions, like the one investigated in this study, are an effective intervention for Chinese families because they offer practical advice and help and provide responses to group members' unmet psychosocial needs, in a more receptive and appropriate manner than that provided by more didactic and directive therapist-led family interventions, such as in psycho-educational programmes.

Contrary to previous findings that Chinese people are uncomfortable about talking of their personal feelings and problems with outsiders (Leung et al., 1993), this study indicates that Chinese family carers are willing to share their experiences openly with those in similar difficult life situations and in circumstances where little help is available from elsewhere. Due to the trusting relationships being built in the early group stage, more than half of the group participants indicated, during the interview, that they felt they were able to speak freely without fear of embarrassment or negative attitudes, or discouragement from other group members. The perceived benefits of a relational social climate within the support group (in Section 8.4.2) in this study, meant that most family carers felt that open disclosure was the best means of gaining support and help and also of gaining trust from other group members who were offering psychosocial support to them.

In Hong Kong, as well as in other Chinese communities, the family unit is the foundation of society and family members have a strong sense of obligation towards other members (Hsu, 1995). Research suggests that if one member of a Chinese family encounters a stressful life event, other members will feel a sense of burden and will act collectively to cope with the crisis (Meredith et al., 1994). A few studies have also shown that this strong collective and interdependent Chinese family culture affects family members' perceptions of their needs and ability to participate in caring for a relative with severe physical or mental illness (Fung & Chien, 2002; Leung et al., 2000). Chinese family members, particularly spouses and mothers, have been found to feel more anxious about how to provide the best possible care to the ill relatives, and are persistent in seeking information about their relative's illness (Leung et al., 2000). In addition, a strong value in Chinese families is family piety, which includes obligation, respect and duty to one's parents (Chen & Davenport, 2005); children are taught to feel an obligation to be their parents' carers. This is consistent with the cultural practice of giving the family name before their first name, through which a family's collective identity and interpersonal harmony is given greater importance than that of an individual family member.

Confucianism, which is often characterised as a system of social and ethical philosophy, is believed to have had a powerful influence on Chinese behaviour for the past 2000 years. The main principles include filial piety, respect for familial hierarchy, discouragement of self-centredness, and importance of interpersonal harmony and collectivism; these are considered principles for social interaction and behaviour (Chen & Davenport, 2005). Similar to these Confucian principles, the mutual support group in this study placed emphasis on mutual respect and collaborative and collective actions, rather than on self-reliance and independence from the group that they belonged to. The family carers were also expected to maintain interpersonal harmony amongst group members, to look favourably on humility and consideration of others' feelings, and to discourage self-centredness and any interference and dishonesty within the group. This collective identity, as well as adding to the trusting and empathetic relationships amongst the support group participants, helped to resolve the fear of open disclosure of their personal, or their family's 'dishonour'. Each group participant also showed acceptance and tolerance of the poor family situations and problems in caregiving of others.

The findings of this study support those of Meredith et al (1994) that Chinese families value mutual obligation and family solidarity, and place more emphasis on interdependence, while Western cultures place more emphasis on independence. Caudle (1993) indicated that Hispanic families, as well as White, non-Hispanic families, all emphasise the importance of obtaining information about patients to maintain their independence. If family support services are to be effective, they must be culturally sensitive (Telles et al., 1995). In Chinese communities, family-oriented mental health services, as embodied in the family support group intervention in this study, may be more effective than the usual outpatient services, in relieving the burden of care for family carers' and in providing them with psychosocial support and care, than other family members or other health professionals.

9.2.6 Group attendance and study attrition rate

It is noteworthy that the average attendance of the mutual support group sessions by the family carers was high (M= 9.0, SD= 1.1; possible range 0 to 12) and only four (10.5%) carers failed to attend the minimum of seven group sessions. In addition, the attrition rate of this study was very low (i.e. 2.6% for only one participant in the control group lost to the study; and increased to 10.5% if those four carers who failed to attend seven group sessions were counted as attrition). This high attendance and low attrition rate of the mutual support group might be the important factors that contributed to the success of the intervention in this study. The attrition rate in this study was also substantially lower than most of the other group intervention studies conducted in Western countries (range 8% - 60%; Asen, 2002) or the studies done on mutual support groups for families of patients with severe mental illness in the USA, UK and other European countries (range 13% - 40%, see the literature review in Section 3.5.2 of Chapter 3).

Despite the low attrition rates, seven of the 38 group participants identified problems in attending the group sessions and particularly the four who had irregular or low group attendance and who gave reasons similar to those given by the families who refused to participate in the group intervention. Their reasons were consistent with the barriers found in any type of family group work (McCallion & Toseland, 1995; Borkman, 1999) and were similar to those found in previous studies (McCann, 1993; Winefield &

Harvey, 1995; Heller et al., 1997), including inconvenient timing or not having enough time to attend, perceived inadequate leadership within the group, feeling uncomfortable with other group members, and not having another person to take care of the patient in their absence. The implication of these findings is that if mutual support group intervention is to succeed, family support services should provide a range of options to take account of service users' preferences and convenience.

However, the high attendance of the support group in this study may be attributable, in part, to the group facilitator being trained and experienced and who operated according to a treatment protocol that was research-based. The low attrition rate of the patients and carers may also be due to the regular follow-up and encouragement given to the participants in the mutual support and standard care groups by the group facilitator or researcher. This was achieved through bi-weekly or monthly telephone contacts during and after intervention, which may have increased the motivation of the participants to continue their involvement in the study. Another important factor may be that the patients' illness had been of a relatively short duration (i.e., 77% of them had been ill for less than three years). These families might have been more optimistic and motivated about the potential for change (Schiff & Bargal, 2000) than families of patients who had a more chronic illness. This also emphasises the need for family support services to offer accessible and early intervention after discharge from hospital (Craig et al., 2004). The peer leader and facilitator of the support group contributed much time and effort in encouraging and assisting group members to attend the meetings, including telephone calls and face-to-face contact with participants and the provision of transport. As a result, there were no initial dropouts from the group. The follow-up and constant encouragement by the facilitator (and other group members) served to reinforce and maintain the effects of the intervention over the follow-up period (Dixon et al.,1999).

9.2.7 Comparison of the characteristics between different models of multiple-family group interventions

The family mutual support group developed and evaluated in the present study is one of several available models of multiple-family educational and supportive intervention for patients with schizophrenia and other psychotic disorders. Other models of

multiple-family group interventions, particularly the psycho-education group programme (e.g. McFarlane et al., 1995), have been evaluated in previous studies and have been adopted as a psychosocial intervention for mentally ill patients in receipt of community care in Western countries. The characteristics of the mutual support group used in this study and those of the four types of multiple-family group intervention used in the United States and European countries, and evaluated in controlled trials, are presented in Table 9.1. The support group and these multiple-family groups share six similar characteristics, which are as follows:

(1) Most carers involved in the groups were women (58% - 88% of the group members, across studies) who were mainly parents, spouse or siblings of the patients. The number of members in each group ranged from 6 to 15.

(2) The group interventions were facilitated or led by one or two trained mental health professionals such as psychiatric nurses and psychologists and some were co-led by experienced family carers.

(3) The interventions were guided by a treatment protocol (designed and tested by the researchers or adopted from a well-established family group programme) and the groups met weekly or bi-weekly. Each session lasted 1.5 or 2 hours.

(4) Content of the interventions comprised knowledge of mental illness and its treatment, community services available, training for effective communication, problem solving and coping skills, and opportunities to share emotions associated with caregiving and experiences of the caregiving role.

(5) The main patient outcome measures used include relapse rate, length of re-hospitalisation and symptom severity (except Solomon et al.'s (1997) study which did not measure patient outcomes). Family outcomes measured include psychological distress or burden and perceived social support. Analysis of the study outcomes was on an intention to treat basis for all studies and over a period of at least 6 months follow-up (or over an intervention period of 1-2 years).

(6) The most frequent significant positive outcomes identified were the reduction of patients' relapse rates and/or length of re-hospitalisation, and there were inconsistent improvements across studies in all family outcomes.

Table 9.1 Characteristics of different types of multiple-family group intervention for people with schizophrenia and other psychotic disorders

Authors	**Present PhD study**	**Szmukler et al. (2003)**	**Solomon et al. (1997)**	**McFarlane et al. (1995b)**	**Montero et al. (2001)**
Country	Hong Kong	UK	USA	USA	Spain
Study design	RCT	RCT	RCT	RCT	RCT
Intervention	Mutual support group for family carers (vs. standard care).	Two-phased family support programme (individual family sessions followed by relatives' groups vs. standard care).	Group family workshop (vs. individual consultation and standard care groups).	Psycho-educational multiple-family group treatment (vs. single-family treatment).	Relatives' group (vs. single-family behavioural family therapy).
Group composition	- 38 family carers of people with schizophrenia randomly selected and assigned to the group - 12-13 family carers per group - One primary carer of each patient included - 58% female, all Chinese carers, mean age 34.9 years (SD= 11.6), mainly spouse, parent or adult child, and living with patient - Average contact time with patient was 3.1 hours per day.	- 30 families of people with schizophrenia (73%) or psychotic disorder randomly assigned to the group - 10-15 carers (and other family members) per group - An index carer (most involved in a caring role) and other family members included - 82% female, 52% white and 33% black carers, mean age 54.0 years (SD= 14.0), mainly parent or spouse - Average contact time with patient varied from <10 hrs (46%) to >35 hrs (26%) per week.	- 67 family carers of people with schizophrenia (64%) or affective disorder randomly assigned to the group - 6-12 carers per group (some were not study participants) - One family member with major caring responsibility for patient included - 88% female, 84% white carers, mean age 55.7 years (SD= 12.5), mainly parent, sibling or adult child, living with patient - No description of average contact time with patient.	- 191 families and their patients with schizophrenia (81%) or other psychotic disorders randomly assigned to the group - 6 families per group, started after 3 weekly single-family education sessions - All family members included - 52% white and 43% African American; other family characteristics not specified - At least five face-to-face contacts per week.	- 41 family carers of patients with schizophrenia randomly assigned to the group - 8-10 carers per group, started after 2 educational sessions about the illness - One carer per patient, occasionally two - 68% female, all Spanish, 43% high expressed emotion, 44% extended household, mainly parent and sibling. - 55% >35 hrs contact time with patient.

Authors	Present PhD study	Szmukler et al. (2003)	Solomon et al. (1997)	McFarlane et al. (1995b)	Montero et al. (2001)
Group process	- 12 bi-weekly sessions (2 hours per session) - Facilitated by a trained registered psychiatric nurse and co-led by 1 to 2 peer participants - A treatment protocol designed and tested by the researcher on the basis of recent literature and family needs assessment for patients with schizophrenia in Hong Kong in 2003 - Time of meeting and topics of discussion decided through agreement of group members.	- 12 bi-weekly relatives' groups (1.5 hours per session), after six weekly 1-hour individual family sessions in their home - Conducted by a trained community psychiatric nurse (carers' support worker) and a carers' representative - Content and time of the sessions scheduled by the research team, after consultation with carers' representatives - Main content of the individual family sessions was: engagement, education, accessing services, and development of effective coping strategies - After an informal chat, each session started with a half-hour talk by a specialist speaker, followed by a general discussion, using a problem solving approach.	- 10 weekly sessions (2 hours per session) - Facilitated by a mental illness specialist and an experienced family carer trained as a peer consultant - Educational content jointly developed by professionals and a family member, based on a stress-coping-adaptation framework. A 132-page teaching manual as a primary resource for facilitating the groups - Time and content of sessions scheduled by the facilitators - Of each session, 30 minutes were devoted to information about mental illness and its treatment and 90 minutes to the development of coping skills.	- 2-year supervised treatment included: three weekly single-family sessions, an educational family workshop and bi-weekly multiple-family group - Conducted by 2 trained family clinicians (social workers, psychologists and nurses) - The treatment protocol was derived from the approaches of Anderson et al. (1986) and Falloon et al. (1984) - Started with 3 weekly single-family sessions; a multiple-family educational workshop presented by the 2 clinicians; and then the multiple-family group met biweekly, co-led by the clinicians - Time and content of sessions scheduled by the 2 clinicians according to the protocol.	- 12-month programme (1.5 hours per session): weekly for the first 6 months, bi-weekly for the next 3 months and monthly for the last 3 months - Developed on the basis of research on expressed emotion and strategy by Leff et al. (1982) - Started with two single-family educational sessions about schizophrenia and followed by weekly to monthly relatives' group, led by 2 therapists (psychiatrists and psychiatric nurses) - An open group: new relatives were incorporated as referred to the programme - Time and content of sessions scheduled by the therapists according to the protocol.

Authors	Present PhD study	Szmukler et al. (2003)	Solomon et al. (1997)	McFarlane et al. (1995b)	Montero et al. (2001)
Content	- Five phases of group development (Kimberly, 1997; Wilson, 1995): (1) Engagement & orientation (2 sessions); (2) Recognition of psychological needs (3 sessions); (3) Dealing with psychosocial needs of self & family (3 sessions); (4) Adopting new roles & challenges (3 sessions); (5) Preparation for independent future life (1 session). - Involved supportive interventions (e.g. ventilation of feelings, sharing and validation of caregiving experience, encouragement for providing care), enhancing individuals' self-efficacy in coping for caregiving, altering cognitive and emotional reactions to stressful life situations, and practice of problem solving strategies (within and outside group) using group members' experiences	- Half-hour talk: consisted of knowledge about the meaning of mental illness, its causes, medication and side effects, psychological treatment, effects of culture; ways of looking after themselves and future life - One-hour discussion: consisted of sharing of feelings and ways of caregiving, both positive and negative; effective communication and problem solving strategies applied to caregiving. - Excluded the patient from the group.	- The objectives were to orientate families about the mental illness and its treatment; help them realise that others in their situation have similar feelings and experiences; and provide guidelines for dealing more effectively with the patient, other family members and the mental health system - Homework was assigned at the end of each session to help members apply the coping skills learned during the sessions. - Excluded the patient from the group.	- The objectives were to reduce symptom levels and frequency of relapses, enhance psychosocial functioning, and lower expressed emotion - The first year of intervention focused on helping the patients re-enter the community by promoting family interactions that supported recovery from the acute episode; and the second phase (multiple-family group) focused on the helping the patients' vocational and social functioning. - Specific interventions were to (1) engage key members of the family; (2) provide information about the biologic aspects of schizophrenia and its treatment, via a standardised videotape, lectures and coping guidelines; (3) intervene early in patient relapse; (4) provide ongoing	- The objectives were to learn problem-solving skills, reduce criticism and over-involvement, reduce social contact between patient and relatives, expand social networks, and lower expectations - Main content: information about the illness and treatment, problem solving skills, building harmonious interpersonal relationships, training in communication skills and emotional expression and control - Excluded the patient from the group.

Authors	Present PhD study	Szmukler et al. (2003)	Solomon et al. (1997)	McFarlane et al. (1995b)	Montero et al. (2001)
Content (cont'd)	- Included the patient during the 2nd and 6th session, which consisted of (a) sharing of information about mental illness, symptoms, illness-related behaviour, treatment & community services available, and their effects on family; and (b) discussion about patients & family carers' physical & psychosocial health needs.			support and formal clinical problem solving; and (5) expand the family's social network. - Included the patient in the multiple-family group intervention (2nd phase of the programme).	
Contact outside the group	- Group members (family carers) were permitted, and were sometimes encouraged, to meet with each other outside of the formal group meetings and to provide practical aids in family and patient care. Many of them had frequent contact outside the group and provided practical assistance to each other - The group facilitator and carer co-leader followed up and encouraged the participants to attend the group in-between group meetings over the period of intervention.	- No description of any contact outside the group - All carers were contacted by mail between group sessions to confirm the speaker and subject for the next session. The carers who failed to attend sessions were contacted by phone by the nurse to inquire as to whether anything had happened. Up to 5 phone calls were made for those who did not attend.	- No description of any contact outside the group and other follow-up contacts by the facilitators.	- No description of any contact outside the group. - Over the 2-year period of intervention, a family clinician was assigned to each family and acted as (1) the patient's primary case coordinator and therapist during inpatient and outpatient phases; (2) the family's educator and consultant, and (3) the principal liaison to the treating psychiatrist and rehabilitation agencies. A full-time psychiatrist provided pharmacologic treatment for the patients.	- No description of any contact outside the group and follow-up by the therapists.

Authors	Present PhD study	Szmukler et al. (2003)	Solomon et al. (1997)	McFarlane et al. (1995b)	Montero et al. (2001)
Main outcomes	- Family outcomes: family burden, family functioning, perceived social support, family services utilisation, and family conflicts - Patient outcomes: patient functioning, symptom severity, and length of re-hospitalisations.	- Family outcomes: psychological morbidity, appraisal of caregiving, effective and ineffective coping, social support, contextual measures of severity of caring difficulty - Patient outcomes: number and length of re-hospitalisations.	- Family outcomes: family burden, stress and grief, social support, and self-efficacy regarding knowledge and skills for caregiving - Patient outcomes not measured.	- Family outcomes not measured - Patient outcomes: rates of relapse & re-hospitalisation, positive & negative symptoms, medication dosage & compliance, & work-related activities	- Family outcomes: knowledge about schizophrenia, psychological distress, & expressed emotion - Patient outcomes: psychotic relapse, symptom severity, social functioning, medication dosage and compliance.
Main results	- Family outcomes: statistically significant improvements in family burden and functioning and perceived social support, and reduction of family conflicts and demands of service utilisation over the 12-month follow-up - Patient outcomes: statistically significant improvements in patient functioning and decrease in length of re-hospitalisation over the 12-month follow-up.	- Family outcomes: no significant changes over time for within the support group and between the support and standard care groups over 6-month follow-up. The whole group of carers in the study indicated a reduction in the severity of caring difficulties and an improvement in coping ability - Patient outcomes: total of three re-admissions in the support group and 6 in the control group. However, length of stay was longer in the support group (M=142.7 days, SD= 41.7) than the control group (M= 33.7 days, SD= 36.6).	- Family outcomes: only significant improvement identified for self-efficacy at intervention termination, in both family group workshops and individual family consultation group; and no significant differences in other outcome measures and at the 6-month follow-up.	- Patient outcomes: significant lower 2-year relapse rates than the single-family intervention, particularly among those with higher symptom severity, and greater improvement in work-related activities over 2 years; re-hospitalisation rates and psychotic symptoms decreased significantly, and medication compliance was high, to equal degree in both interventions.	- Family outcomes: significant reduction of expressed emotion and increase of knowledge; the behavioural management group indicated greater improvement in expressed emotion - Patient outcomes: significant reduction in relapse rate and symptom severity, and improvement in social adjustment. No significant differences between most measures, but more improvements in symptom severity, medication dosage and social adjustment in behavioural group.

Authors	Present PhD study	Szmukler et al. (2003)	Solomon et al. (1997)	McFarlane et al. (1995b)	Montero et al. (2001)
Cultural considerations	- The treatment protocol was designed on the basis of a family needs assessment and amended according to the feedback of 24 family carers in the pilot testing - In each session, family issues and difficulties specifically related to patterns of Chinese family relationship, communication and concepts about mental illness were discussed; and open sharing and understanding about individual concerns and cultural issues were set as one important goal of the second group phase (Session 3 to 5).	- The intervention was designed to appeal specifically to ethnic minority carers. The researchers consulted with local community representatives who suggested that food, information and education should be a prominent focus of the group meeting.	- No specific consideration of cultural issues made on the design of the interventions	- No specific consideration of cultural issues made on the design of the interventions	- No specific consideration of cultural issues made on the design of the interventions, except strategies to lower the level of expressed emotion in the families.
Group attendance and dropout	- Average group attendance was 9.0, ranged from 4-12 sessions; four attended <4 sessions. - All completed the intervention and 12-month follow-up.	- 16 carers (53%) attended half or more; 5 (17%) attended none. - 26 (87%) completed the 6-month follow-up.	- 5 carers attended less than 7 sessions; 20 carers (30%) dropped out by the end of the workshops - 43 carers (64%) in the family workshops completed the 6-month follow-up	- 24 families (29%) discontinued participation during the 2-year period and 70 (84%) remained in the final analysis.	- 6 carers (15%) dropped out in the programme having attended less than 75% of the sessions - 21 carers (51%) completed the intervention and follow-up.

As shown in Table 9.1, the mutual support group evaluated in this study was distinct from the other multiple-family group interventions for schizophrenia in several respects. These unique characteristics might possibly help to explain the positive changes in a wide variety of study outcomes among the family carers, the patients and other family members over the 18-month study period, in contrast to the less positive changes found in other similar studies. These unique features of the mutual support group used in the present study included:

First, more flexibility than in other multiple-family group interventions in the timing and duration of meeting and selection of topics of discussion in each session, which were decided through agreement of group members and provided in the mutual support group. As a result, the family carers experienced freedom of choice in what they discussed, with the result that they might have experienced a greater sense of control over their own decision and a greater sense of belonging to and participation in the activities and events of the support group.

Second, the participants (family carers) in the mutual support group emphasised the importance of individual problem solving, sharing of experiences and provision of practical aids to one another, both within and outside the group, to a greater extent than participants in other types of support group researched previously. The group participants were permitted, and were sometimes encouraged, to meet with each other outside the formal group sessions. The perceived benefits of social contact and practical assistance between the group members outside the group meetings in dealing with immediate and important caregiving difficulties and problems were emphasised and positively appraised by the family carers during their individual interviews and there was evidence for this also from the tape-recorded data of the group sessions. It seems plausible that this enthusiastic, collective and practical support, experienced by participants both within and outside the support group, met the psychosocial health needs of the Chinese families involved. In addition, the group facilitator and the carer co-leaders maintained constant bi-weekly follow-up of all family carers in the support group. They encouraged the carers to attend the support group and provided them with assistance or referral for any difficulties in caregiving as required.

Third, expansion of the social support networks of group participants was also encouraged during the support group meetings. It seems possible that extension of support networks might have enhanced the perceived social support and integration between the family carers, other family members and their close friends. As a result, the benefits of attending the mutual support group were extended outside the family group and enhanced the substantial effects of the intervention. This mechanism is suggested by McFarlane (2001) from his study of family group work as one which can potentiate the effects of a group work experience; and has been recommended also by Montero et al. (2001).

Frequent social contacts outside the group and expansion of the social support networks encouraged among the family carers and the group facilitator are important unique characteristics of the mutual support group in the present study. These unique features might explain the fact that, even though the mutual support group in the present study only included the index carers (most involved in caregiver roles within the family) and excluded the patients in most of the group sessions, the benefits of their participation in the support group were able to extend to their patients and the entire family. These mechanisms are also consistent with Chinese culture and family practices, that Chinese people have a strong sense of kinship and cohesiveness with their extended families (Lee & Liu, 2001); and they prefer and benefit more from collective, inter-dependent and practical assistance and support than from frequent discussions and sharing of problem-solving techniques and successful caregiving experiences during the group sessions.

Finally, specific cultural considerations were taken into account when designing the group intervention, to a greater extent than multiple-family group interventions evaluated previously. The treatment protocol was designed on the basis of an educational needs assessment of Chinese families caring for a relative with schizophrenia with similar cultural and socio-demographic backgrounds, and was amended according to the feedback of the carers in the pilot study. In each session, family issues and difficulties specifically related to patterns of Chinese family relationship, communication and concepts and beliefs of the mental illness were discussed; and open sharing and understanding about individual concerns and cultural issues were set as one important goal of the second group phase (sessions 3 to 5). As suggested by Telles et al. (1995), the advantage of multiple-family

groups occurs most dramatically when the cultural issues of caregivers, patients and the entire family can be carefully considered and addressed in the group meetings.

9.2.8 Clinically significant changes in families' psychosocial health statuses

Treatment effects are often derived from statistical comparisons between mean changes resulting from the treatments under study or, more recently, by calculation of the size of an effect (i.e. effect size). This use of statistically significant tests to evaluate treatment efficacy is limited in at least two respects: (1) the statistical tests provide no information about the variability of response to treatment within the sample; yet this variability of treatment outcome is of the utmost importance to the researcher and service provider (Jacobson & Truax, 1991); and (2) the existence of a treatment effect has no bearing on its size, importance, or clinical significance; that is, it tells very little about the practical importance of the intervention effects, such as its impact on individual clients or how many of the participants returned to normal functioning afterwards (Jacobson et al., 1999). Although large effect sizes are more likely to be clinically significant than small ones, even this relationship may not necessarily be true.

The degree of clinically significant change was therefore used in this study to measure the important changes in health status of the family carers and their patients and to investigate whether carers' psychosocial conditions returned to a normal range of functioning, or their presenting psychological problems were resolved. This criterion of return to normal range is stringent but it is important for health professionals, as well as for consumers of mental health services, to know how often an intervention results in an individual returning to normal functioning (Speer, 1998). For the mutual support group used in this study, the clinically significant changes in the functional state of the families of patients with schizophrenia from the baseline measurement were evaluated using the two-fold criterion. That is: (a) the mean difference from baseline to at least two standard deviations; and (b) the magnitude of change to be statistically reliable by calculation of the reliable change index of at least 1.96, suggested by Jacobson et al. (1999). According to this criterion, the clinically significant changes in family functioning (mean difference= 4.1, whereas clinical significant difference, CSD= 2.0; Reliable Change Index, RCI= 4.1) and patient functioning (mean difference= 21.7, whereas CSD= 17.1; RCI= 2.1) were

found at 6-months after intervention; and the significant changes in family burden (mean difference= 5.7, whereas CSD= 5.2, RCI= 2.2), family functioning (mean difference= 5.2, RCI= 3.5) and patient functioning (mean difference= 26.3, RCI= 3.1) were also found at 12-months following the intervention.

The variability of the effects of the mutual support group intervention in this study was also evaluated by examining the change of mean scores at an individual level. The results showed that 26% to 58% and 53% to 79% of the mutual support group participants reported clinically significant changes in the direction of functionality (i.e. two standard deviations from the baseline) on family burden and functioning and patient functioning at 6-months and 12-months after intervention, respectively. However, less than one-quarter (13% - 24%) of the group participants reported clinically significant changes of the three functional states at one-week after the group intervention. These results showed that a higher percentage of family carers and their relatives with schizophrenia reported clinically significant changes in psychosocial functioning at the six and 12 months follow-up (increased three and four times, respectively), than that at one-week after the support group. These findings demonstrate that a mutual support group intervention of the type used in this study is able to produce a consistent and substantial clinically significant improvement in the psychosocial functioning of family carers and their patients over time. Moreover, the magnitude of these changes can be seen to be statistically reliable.

The positive effects of the mutual support group on the functional state of family carers and their patients were shown over a longer period of post-intervention, (i.e. there was a greater effect at 12 months than at one week or six months after intervention), and this was consistent with the statistical results of the repeated measures presented by MANOVA in Sections 9.2.1 and 9.2.4. These results are encouraging when it comes to the community care of patients with schizophrenia and indicate that mutual support groups for families of such patients can show increasing substantive positive effects on them and their patients' functional state over a one year period of follow-up, that are both statistically and clinically significant when compared with standard community mental health care. The evaluation of clinically significant change in recipients' psychosocial health status is a meaningful way of determining the practical importance of statistically significant differences between groups under study (Tingey et al., 1996). In addition, it

also has importance when it comes to understanding the variability of psychosocial outcomes within a treatment condition (Jacobson et al., 1997).

The clinical significance of a psychological treatment or intervention refers to its ability to meet standards of efficacy set by health care consumers, clinicians and researchers. All of the parties may have similar interest in seeking to assess important clinical changes in the functional status of recipients under treatment, rather than by their statistically significant changes alone. Clinically significant change in a treatment outcome indicates either a therapeutic effect, or a meaningful change in a recipient's presenting problem, that relates to the return to normal functioning or getting rid of the problems that the client brought into the intervention (Jacobson & Traux, 1991). When norms on the outcome measure for both dysfunctional and normal populations are not available, the approach used in this study was able to address some basic but important practical issues of clinical significance for a support group intervention; for example, the overall group mean and proportion of families who ended up in a range of well-functioning or normal health states after the intervention was able to be calculated, using the support of a statistically reliable magnitude of change (a reliable change index).

9.2.9 Summary

In sum, the statistically and/or clinically significant results of this study support the effectiveness of a mutual support group intervention for family carers of people with schizophrenia in a Chinese community. The results indicate that this group intervention has positive effects on family burden and functioning, perceived social support, amount of conflicts between family members, patient functioning and re-hospitalisation, and service utilisation, over the 12-month follow-up period. With continuous encouragement for participants to regularly attend and actively engage in a support group especially by peer members and the group facilitator, mutual support can improve the psychosocial functioning of families caring for a relative with schizophrenia without any increase in their demands for community mental health services. The study also provides health professionals with an empirically tested protocol for providing an effective multiple-family group intervention. Therefore, mental health professionals should consider integrating the mutual support group intervention into routine clinical practice and

psychiatric rehabilitation, as this may enhance family-centred care for schizophrenia in Hong Kong and in other Chinese populations.

Through participation in a mutual support group, family carers (and other family members) are able to receive adequate psychological and social support as well as appropriate knowledge and community resources which they can utilise to manage the strains and burden of caregiving and these supports will protect the family unit from major psychological distress during times of crisis and hardship (Saunders, 1999). As family carers sometimes find it difficult to get adequate social support from health professionals, the mutual support group has the advantage of being able to respond directly to the needs of these family carers by making social support available to them from other carers with similar caregiving situations.

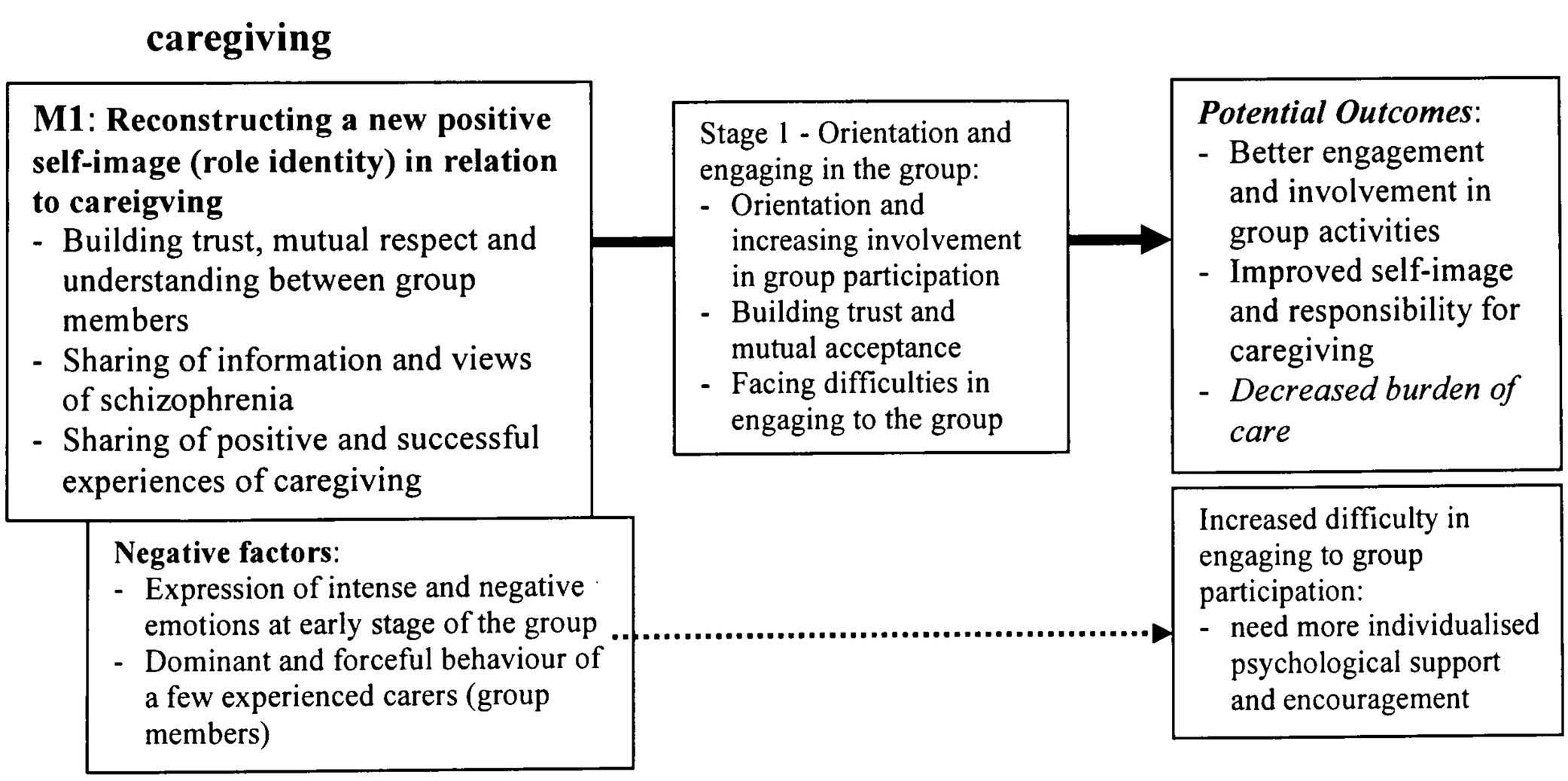
The Department of Health, UK (2001) recommended that a new approach to chronic disease management was needed in the 21st century and that was more than just patient education aimed at treatment compliance among the patients with chronic illness. Instead the introduction of user-led mutual support group interventions, such as in this study, was needed for families of different patient groups with chronic and severe mental or physical illness and these should be valued and encouraged by health professionals. Mittelman (2005) in his review of recent studies on psychosocial interventions for family carers, also suggested that innovative methods of intervention such as peer support groups and web-based support programmes that are individualised and flexible and provide long-term support, appear to show promise and to be feasible in community care. When health professionals are allowed to be members of support groups, so as to enable them to perform advisory roles or facilitate the treatment process, family carers in a mutual support group are able to take more initiative in mutual peer help and support and thus, possibly through their own efforts, can create substantive positive effects on reducing their families' distress, improving patient and family functioning, and enhancing their coping and self-efficacy in caregiving.

9.3 THERAPEUTIC MECHANISMS OF THE MUTUAL SUPPORT GROUP

This thesis is one of the relatively few which have sought to identify the perceived therapeutic mechanisms and limitations of a mutual support group for family carers of

people with schizophrenia in a Chinese population. Lehman and Steinwachs (1998) and Brooker (2001) suggested that the hesitation of clinicians to use family intervention might be attributed to the inadequate knowledge of researchers of the particular elements of family intervention that enhance its therapeutic value for family carers and patients. Increased understanding of the active components of family intervention, such as are seen in the mutual support group in this study, will facilitate the design of future interventions for family carers of the mentally ill and thus produce optimal benefits for patients and their families (Chien & Chan, 2004). Four therapeutic mechanisms were identified from the main themes that emerged from the interview and group session data. The four mechanisms of the support group, their related factors in the stages of group development and their potential outcomes were summarised in Figure 8.1 (in Section 8.5). They are discussed in the following sections, in relation to the recent literature. The flow diagram of each mechanism, showing its main components, is reproduced as parts of Figure 8.1 at the start of each section.

9.3.1 Mechanism 1: Reconstructing a new positive self-image in relation to caregiving



The first therapeutic mechanism mainly refers to changes in the perception of and the nature of the role of family carers in caring for a relative with mental illness that is induced by participation in a mutual support group. Like their patients, the family carers felt "stigmatised and socially isolated by relatives and friends". They emphasised that the

major contribution of the mutual support group to those with these perceived negative attitudes, was to enable them to "reconstruct a new positive identity and self-image". Consistent with the findings of Cook et al. (1999) and Yalom (1995) on therapeutic groups for chronically ill patients and their families, the participants emphasised that interaction with others who were experiencing similar life problems and the feeling that they were "all in the same boat" was useful in establishing group collectiveness, empathy and a trusting relationship between participants. In other words, the 'universality' of the problems or concerns induced a sense of security and respect between the participants. Willingness to share their experiences and offer help to each other (i.e. the 'altruism' factor) as suggested by Yalom (1995), appears to have been an effective way for the carers to maintain their psychosocial health (also see Section 9.3.1). The carers in this study helped each other through the hardships of their stigmatised self-image or 'label' of being a family member of a mentally ill person while supporting each other wholeheartedly in performing their caregiving role.

As a result, the carers began to recognise that they, too, could achieve "what the others had attained in caring for their family and patient". They said they felt more positive about self-image and about the "importance and responsibility of their role in caring for our patient", and they acquired an insight into having a more meaningful life, even though some of their difficulties might remain unresolved.

Kurtz (1997) suggested that mutual support is commonly accepted as the process of sharing common experiences, situations and concerns by people within a group, in which participants can learn from one another about how to cope with their own problems, and also about how to care for and be concerned for, other group members. A mutual support group can thus be referred to as a type of mutual helping unit, where participants share and deal with common health needs and concerns and voluntarily offer reciprocal support and satisfy common goals (Nichols & Jenkinson, 1991), thereby bringing about desired social and personal changes (Oka, 2003).

Enthusiastic and autonomous interchange of information and practical skills regarding patient care provision was important for the family carers in this study, as it enabled them to adapt to the new role and responsibility of caregiving for their mentally ill relative. Imparting information about the illness and patient management, identifying

available community resources, and sharing successful and unsuccessful caring experiences, were important components of the mutual support group in this study. Sharing information and disclosures about their differing perspectives on caring for their relatives with schizophrenia, by the group participants, is important for family carers, particularly for those with limited caregiving experience, or inadequate knowledge about mental illness. It also helped them make sense of the reality of the illness, as well as giving them plausible explanations about their responsibilities for patient care (Heller et al., 1997b; Humphreys, 1997). As a result of this interchange, family carers gained experiential knowledge from those who had lived through and resolved their own life problems, and this was knowledge that would not have been available from health professionals (Heller et al., 1997b).

This group behaviour helped to change the family carers' perceptions of their patient's illness and its management, and facilitated them in reconstructing a new positive personal identity. Prior to their participation in the group, family carers in this study had little knowledge about the illness and had found their sense of self being diminished through misunderstandings and distress, caused by their inexpert manner of care delivery. However, *their self-image changed progressively as they learned about the reality of the illness and gained useful insight into their responsibilities and the difficulties of caring for their patient*. These positive changes revealed the effect of the mutual support group in improving the adaptive competence of family carers in dealing with short-term crises and life transitions as well as the long-term challenges, stresses and privations (Gazda, Ginter & Horneboston, 2001).

Sharing of information about the illness can also be crucial for clarifying misconceptions about the causes of schizophrenia for the family carers. For example, participants in this study, confronted with emotions of shame, guilt and anger, also experienced feelings of uncertainty (Barrowclough & Tarrier, 1992; Medvene & Krauss, 1989), because they thought they were required to be responsible for the illness within their family. Through participation in the support group, the group members had the opportunity to think about and share experiences of different ways of doing things and to discuss the pros and cons of their actions. This led to improved psychological well-being and ability to cope with the stigma related to the illness. Mutual support groups are

therefore viewed as social worlds, in which the group is a cultural arena with no formal boundaries and whose members were able to attach definitions (and redefinitions) and symbolic meanings to things that are usually unknown or are unfamiliar to outsiders (Smith, 1991).

Borkman (1999) suggested that the sharing of caregiving experiences, combined with open discussion about the adverse life situations encountered in caregiving, assists participants in the mutual support group to reframe their life problems and enables them to pinpoint 'what is wrong', or not working, in their management of their relative with schizophrenia. Even though family carers recognise that they will have to continue to live with unresolved difficulties, they are able to gain an insight into a more meaningful life and thus gain relief from thinking of themselves as the victim of the illness and begin, instead, to act compassionately towards their sick relative. This reframing of problems and 'letting go' of unsuccessful methods of caregiving is considered crucial by family members for coping effectively with their patients with schizophrenia and other severe mental illnesses (Gazda et al., 2001).

As discussed in Section 9.3.1, the family carers' adoption of a new role and more effective coping methods of caregiving, resulted from the group members' sharing their past personal experiences and caregiving difficulties within the supportive group environment. Family carers' experiential learning started by listening to the personal stories of other group members, from which they learned about communication with their patients and/or other family members. This continued with stories about how support group members had attempted different means of communication and ways of resolving arguments and conflicts with their family members, which had mainly arisen from miscommunication and misunderstandings.

Galinsky and Schopler (1995) and Powell (1994) suggested that, in the experience of their family group, mutual sharing of personal knowledge and experiences among families within a support group is one way of demonstrating their mutual concern and care for each other and, through these social interactions, they are able to practice effective communication with other people. This suggestion is confirmed by similar comments from the interview data of 10 family carers in this study. These family carers also emphasised that adequate opportunities to practise alternative styles of communication and behaviour,

enabling them to interact more effectively with their patients and other family members, and deal with problems and conflicts with them, was important in their successful *adoption of a new caregiving role*.

The findings in this study also suggest a need for continued group participation or a longer period of group development for those few participants who had been less actively involved in the group, or who had made slow progress in accepting the experiences and responsibilities of caregiving. It was sometimes difficult for these participants to build a sufficient level of mutual trust and support to discuss the 'taboo areas' of their family life, within the six-month group intervention. Consistent with the recommendation by Wilson (1995), a minority (three) of the carers in this study indicated that more work was needed to overcome these difficulties, for example, by having more discussion, both within and outside the support group, about the actual scenarios encountered by family carers and organising more outside group contacts and activities. These families might also need more intense individual support from the facilitator and peer leader of the group.

This improvement in carers' self-image and in their caregiving role occurred mainly during the first stage of group development. This initial stage was perceived by family carers as critical and essential to them in building trust and acceptance of each other's role and responsibility in the support group (see Section 8.3.1). Once they were successfully orientated towards and involved in participation in the group, they felt comfortable enough to discuss openly their own family issues, and thus to engage actively in the mutual support group and in other social activities outside the group. Yalom (1995) suggested that feelings of mutual understanding and acceptance and subsequent increased empathy with each other's life situation, is the first and most important step towards the successful integration into a therapeutic group. Without mutual trust and acceptance between them, group participants would neither disclose their own personal issues and feelings, nor listen to or care about other members' needs and concerns (Wheelan, 1994).

Two negative factors were identified as having hindered the carers' engagement in the support group. They included the expression of intensive and negative emotions by members in the group sessions and the presence of dominant and forceful behaviour by a few experienced carers within the group. It might have been better if sharing of very

intense and negative emotions about family situations had been left to the later stages of the mutual support group, so that the members had more time to establish adequate social support for each other before facing these painful experiences and emotions. The importance of group members and the facilitator being alert to the need to offer positive, concrete support and to demonstrate effective coping methods is highlighted in the literature of family group work (Powell, 1994; Wilson, 1995). Thus, emotionally weak members become aware that their family situations are not as helpless and hopeless as they previously believed. These patterns of interactions have been highlighted in the literature (Gazda et al., 2001; Yalom, 1997), which offers some guidance on the role of a facilitator within a mutual support group. Yalom (1997) suggests that the group facilitator must be aware that the presence of dominant, forceful and critical group members in such discussions can be discouraging to other members, particularly those who feel more powerless and helpless. Therefore, more positive and balanced views about personal and family situations should be addressed and discussed within the support group as a whole, with appropriate reinforcement from the facilitator and other experienced carers, before the weaker group members can start to accept their stigmatised self-image and false beliefs about the illness permanently.

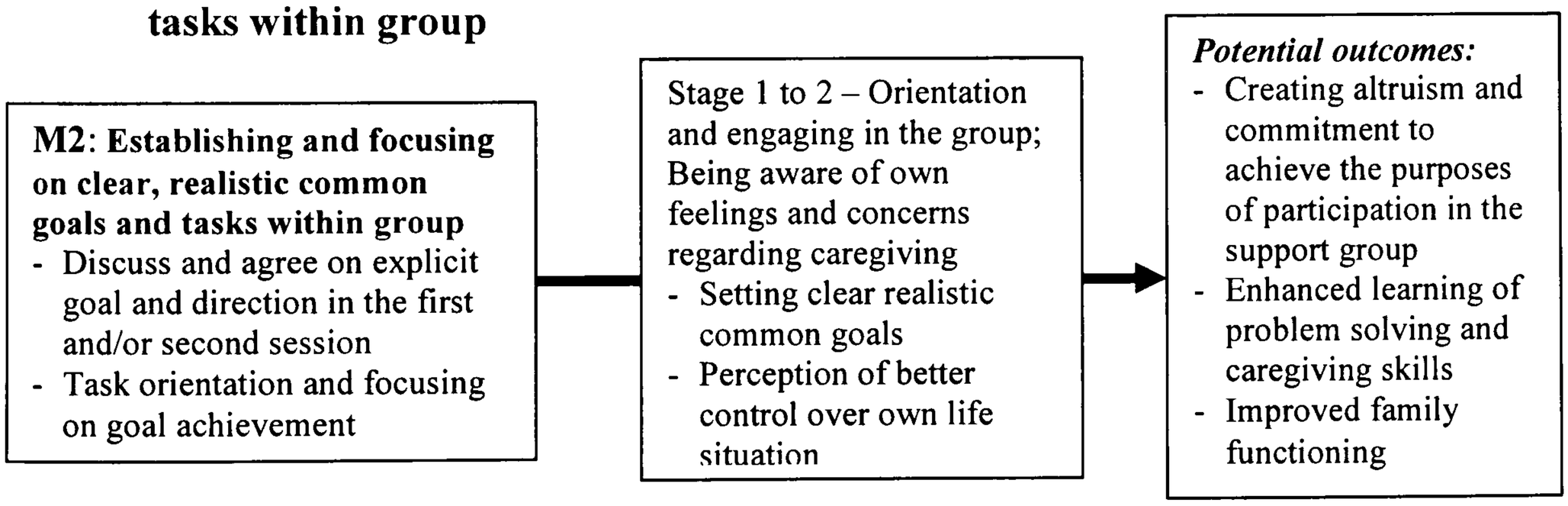
These negative factors were also identified by Mankowski et al. (2001) in self-help groups dealing with alcoholic patients and also by McFarlane (2002) in family psycho-educational groups for patients with severe mental illness. The difficulties of engaging in group participation experienced by five family carers in this study, suggests that individualised psychological support and encouragement should be provided for those members who feel uncomfortable in open self-disclosure within a support group, so as to reduce their tensions and anxieties during the early days of their group participation. Meissen and Volk (1995) suggested that these barriers could be anticipated and reduced, both by group participants and the facilitator if, during the group sessions, they actively encouraged the group's development and individual participants' involvement.

Engaging participants in a support group is the first important, but often difficult, step towards gaining their commitment (Cragan & Wright. 1999). Group participants themselves perceive this as the most important first step and other factors, such as providing more time and opportunity for each participant to express their own feelings and

concerns in the first and second meetings (suggested by the participants in this study), are all matters that should be carefully considered by health professionals when designing a mutual support group for family carers of patients with schizophrenia.

Family carers are confronted with emotions of shame, guilt and anger because they think take the blame personally for the mental illness within their family (Barrowclough & Tarrier, 1992). Cook et al (1994) demonstrated that providing more opportunities for them to vent their feelings and have people in a support group actively listen to their concerns, conveys to them the message that they are of concern to, and are respected by the other members of the support group. This will *lessen their feeling of burden of care* (Cook et al., 1994). This is also a good place for family carers to begin building sufficient trust to be able to disclose their own family issues to other group members. One of the main purposes of a family support group is to help carers cope better with the stress of their caregiving, thus group participants (carers) are required to initiate help and support to other members while, at the same time, gaining benefits themselves from the mutual 'give-and-take' culture within group (Citron et al., 1999).

9.3.2 Mechanism 2: Establishing and focusing on clear, realistic common goals and tasks within group



The second therapeutic mechanism of the mutual support group was establishing and focusing on clear, realistic common goals and tasks within the group. Based on the findings on the positive characteristics of the support group (see Section 8.4.2), common goals, action plans, rules and agreed social conduct, set at the early stage of group participation, were important to the group development, and thus of benefit to the participants. Gidron and Chesler (1995) suggest that a high degree of consensus among all group members on goals and expected behaviour and tasks to be performed in subsequent

group sessions, can increase their feelings of cohesion and belonging to a support group. Thus, this can create enthusiasm and commitment to achieving the common targets and tasks set by the group.

Achievement of these common goals and tasks, which are concerned mainly with information acquisition, emotional responses and practice of patient and family care in a support group, can also enhance carers' own sense of efficacy as well as enhancing their practical caregiving skills in their real life situation. As a result, family carers will be better able *to perform their family caring role and achieve the main objectives of their group participation.*

Consistent with the findings of Chou et al (2002) in their study on family support groups, the family carers in this study showed an unselfish regard and dedication to the welfare of other members in the group. This is referred to as 'altruism', which, as suggested by Yalom (1995), was one of the most important components of a therapeutic group. This altruistic behaviour emerged during the second stage of the group's development (third and fourth group sessions). From the group participants' interview data, it can be seen that the de-marginalising or reconnecting effect of being in a group happens because participants feel they are on common ground with others who are in similar caregiving situations; for example, "... there is no competition to become successful because we are 'all in the same boat.'" Showing carers that they are not alone and that other people have had, and perhaps still have, similar problems and that, with help, these problems can be overcome, allows the individual to gain a renewed sense of self-esteem as a competent, autonomous actor in his or her own life.

While working through these common goals and agreed action plans, a set of meanings and beliefs were gradually created around participation in the group, as the repeated testing of behaviour and responses as well as evaluation, began to take root in the lives of the group members. Group therapists such as Borkman (1999) and Wilson (1995), have suggested that this emergence of meaning in conjunction with group participation was found to occur in parallel with the phases of group development. In addition, the internal affiliation between group participants appeared to develop gradually and was ongoing until the end of the group intervention. Therefore, the continuation of group participation for a longer period of time (than the 6-months intervention in this study) on a

voluntary basis, for example at least nine months as recommended for family psycho-education groups (Chien & Chan, 2004), may produce even more substantial benefits for family carers in caring for their relative with schizophrenia.

Moreover, establishing clear realistic goals that were agreed by all group members was considered by the participants and the facilitator to be one of the key factors in persuading the carers of the benefits and success of taking part in the mutual support group. This important factor has also been identified by Biegel et al. (2004) and Citron et al. (1999), in their studies on mutual support groups for families of people with severe mental illness. It emerged from the interview and group session data that this element, together with the openness of the members in sharing their caregiving experiences, contributed significantly to the positive social climate and sense of cohesiveness within the group.

Task orientation and focusing on goal achievement were common themes for the family carers in the mutual support group in this study. These themes demonstrate the emphasis that the support group placed on problem solving and the learning of specific skills for patient care from other group members. Previous research in this area has demonstrated that the emphasis on learning, problem solving and caregiving skills is crucial to achieving family carers' goals for participation in a mutual support group, and is also the main purpose of the support group (Moos, Finney & Maude-Griffon, 1993).

For family carers, like those in this study, learning to take care of their relative with schizophrenia should be the main aim of their participation in the support group. This educational need is met mainly by the group participants themselves and sometimes through intervention by the group facilitator, together with adequate information about the illness, medication and treatment plan and instruction in effective ways of coping and problem solving skills for caregiving (Wituk et al., 2002). As they become more involved in the support group, positive partnerships evolve between family carers, peer group members and the facilitator, and even with their patients. These relationships *facilitate learning and the practice of problem solving skills within the family situation.* The findings of this study indicated that the experienced family carers were able to involve themselves in, and engage with, the family relationships of those group members who were in need of practical assistance and support. They were able to invite the carers' cooperation in clarifying the roles of individual family members and then in establishing

ways of working together in providing care for the patient and, also, in demonstrating and practising more effective coping skills for caring for their family (Schiff & Bargal, 2000).

The establishment of common goals and a willingness to participate in group activities and tasks were found mainly in the first and second stages of development of the mutual support group in this study. Besides orientation and engagement in the group, another important activity was to discuss and establish a few realistic and explicit goals to be achieved by all group participants. This is considered to be a critical element of the success of a support group because goal setting and its achievement by all group participants is important for not only the satisfaction of group members in their learning of caregiving skills from others, but also for enhancing their feeling of cohesiveness and membership of the support group (Citron et al., 1999).

In the second stage of group development, the family carers participating in the support group in this study became more concerned about how much control they had, (or did not have), over the events and activities in the group. They wanted to participate in making decisions about the activities that would be undertaken in each group session. As a result, having started from a position of powerlessness in the early group sessions, they were able to learn, subsequently, how to be more in control of their own events.

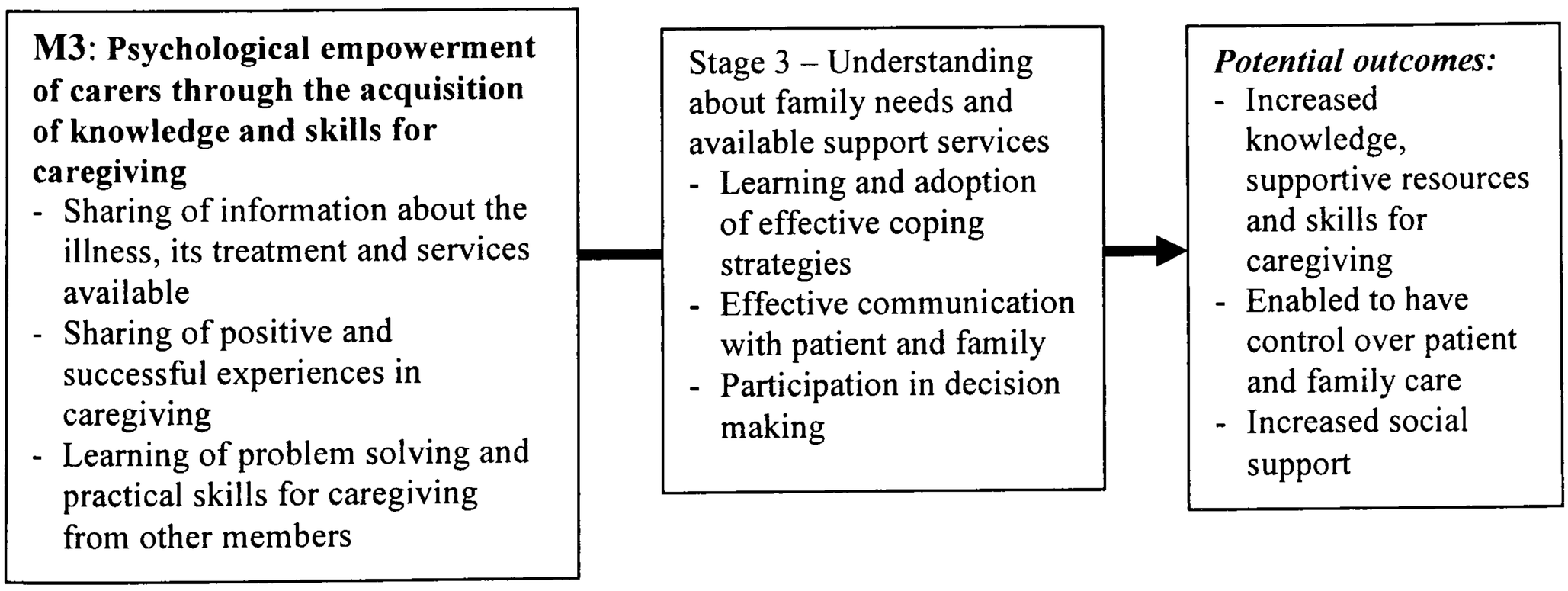
The interview data indicated that when the family carers felt they had more control over their own behaviour and the activities in the support group, this enhanced their feelings of self-efficacy in determining and handling their own life events and caregiving situations at home. Caprara and Steca (2005) suggested that an individual's positive evaluation of life's situations, combined with high self-esteem and optimism in being able to manage his/her own and family events, are the best cognitive components for maintaining and promoting subjective well-being and satisfaction with life. It is important to observe, from the interview and group session data in this study, that the mutual support group was able to help the family carers adopt more efficacious strategies in pursuing their goals and thus to feel more in control of their own life events.

Kernis (1995) suggests that this positive thinking boosts a person's self-esteem and results in them being less prone to giving up in the face of adversity. Mutual support groups, therefore, have the potential to improve coping skills and promote well-being for family carers of patients with severe mental illness. This is relevant to the research

findings on psychological functioning and positive thinking, which concluded that even problematic aspects of individual experience may be better addressed by acknowledging, strengthening and promoting potential coping skills, than simply by helping the person to feel good (Caprara & Steca, 2005; Kimberly, 1997).

In addition, a few of the active and more experienced family carers in the interviews and the latter group sessions, mentioned that their participation in decision-making introduced more flexibility into the group process, better consensus among group members and increased team spirit. Participating in a support group not only imposes an obligation on family carers to make a meaningful contribution towards establishing friendships, but it also obliges them to take a lead in reaching a consensus or a decision when it comes to making a decision about their own events that come up for discussion in the group. As such, the self-help group can be seen as a social system that draws together a group of individuals who are united by social relationships, and who work on tasks according to their common interests and by agreement amongst all members (Borkman, 1999). The work of a family-led support group, with its more self-determined, flexible and interactive process might be a more independent and client-centred model of intervention than the partnership model of care between professionals and clients (Wituk et al., 2000).

9.3.3 Mechanism 3: Psychological empowerment of carers through the acquisition of knowledge and skills for caregiving



The third therapeutic mechanism refers to the potency of psychological empowerment that family carers gain in a mutual support group. The essence of

empowerment, which is to enable the families to help themselves (Gidron & Chesler, 1995), occurs when the family carers gain more knowledge about caring for the patient and then practice effectively the skills that they have learned from other group members in their family situation. Similar to patients with schizophrenia in Wong and Chan's (1995) study, most of the support group participants in this study reported gaining a great deal in their ability to reach out to others, despite being shown clearly that they were suffering from difficult life circumstances that were unlikely to be resolved very soon. Nevertheless, this group was able to bring about *changes that allowed them to cope with their life situations more positively*.

Psychological empowerment at an individual level claims to build on the supportive social context of the group to enable connections with people outside it. Participation in a mutual support group is a social action process, by which individuals learn to gain personal control over issues that concern them, together with a proactive approach to life and a critical understanding of their intrapersonal and social environment (Zimmerman, 1995). This idea has been applied in the USA in an organisational study by Maton & Salem (1995), on a mutual support group programme (named GROW) for people with mental illness. They suggested that empowerment in a mutual support group can be enhanced by provision of a peer-based support system, allowing individuals to take on meaningful roles within the group and within their own family, together with the adoption of a belief system that inspires members to strive for better mental health. From the perspective of empowerment, Reissman and Carroll (1995) suggested that mutual support groups enable participants to take control of their life situations and, as a result, cope better with their caregiving role. As indicated in the group session data, members identified what their personal goals were in relation to caregiving and decided what they wanted to learn and obtain through their participation in the group. Participants also gained increased awareness about the availability of external support resources, such as emotional and instrumental support from family members and others in their social network, and expert advice from healthcare professionals. Such resources could thus be used more appropriately by the families and might result in a reduction of their demands for family support services over the 12-month follow-up period.

Although a small-sized mutual support group may not be as developed, for

example, as an Alcoholics Anonymous group, Zimmerman (1995) suggested that its members would still be able to benefit from opportunities to form new social relationships that would connect them to new people and ideas. As with most of the family carers in this study, most support group participants were able to learn and practise problem-solving skills through actively involving themselves in the group's activities.

As an intervention aimed at empowering its participants, mutual support groups provide opportunities for family carers to develop, with peer support, new knowledge and caregiving skills for their relative with schizophrenia while, at the same time, helping them to establish a more harmonious family life. Another benefit is that, with this newly found knowledge and confidence, family carers also learn to engage with professionals as collaborators, as opposed to engaging with them as authoritative experts (Perkins & Zimmerman, 1995; Wituk et al., 2000).

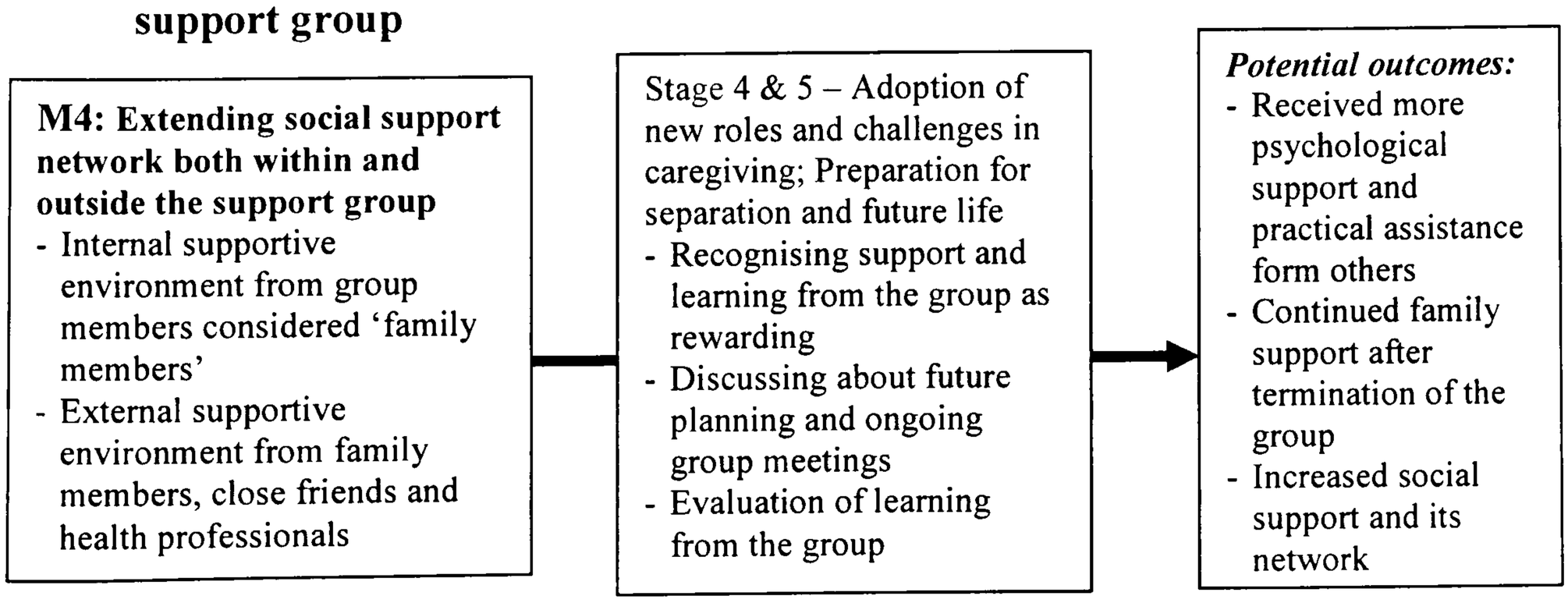
The families in the mutual support group learned to employ active and interactive coping strategies more frequently, such as exploring in-depth the nature of the problems they encountered in caring for their patients and discussing different ways of coping with their caring role. The development of psychological empowerment in the family carers, thanks to the excellent and appropriate ongoing support from other group members, was crucial in strengthening their resistance to feelings of despair and in overcoming their wish to relinquish their caring role. Their confidence increased as their knowledge and caregiving skills grew and, gradually, they became sufficiently confident to take action, both for themselves and on behalf of their family members. The increased social support they received from other group members, whom they came to treat as close family members, continued to encourage them to improve their caregiving skills and, also, to assist them *to be more responsible and effective in their caring role*.

Despite some minor difficulties such as conflicts between group members, the family carers' empowerment grew as they started to better understand their own family needs, and the range of support services available for them. They all acknowledged that it was in the third and fourth phases of the support group investigated in this study, that the most important and rewarding stages in their group participation were achieved, in respect of their caregiving. By that time, most of the carers, in particular the novice ones, were able to learn and adopt new coping strategies and caregiving skills for their patients, in

addition to learning more effective communication with their patients and other family members. Citron et al. (1999) and Chou et al. (2002) suggested, in their evaluation studies on mutual support groups for family carers, that the most frequent and important perceived benefits of group participation included enhanced stress-coping skills in relation to caregiving and the use of a problem solving approach in resolving difficulties in family situations. The family carers in this study also learned to undertake positive activities with their ill relatives, such as accompanying them to follow-up outpatient clinics and participating in recreational activities organised by community centres.

Katz et al. (1992) emphasised that the two most important attributes of a mutual support group are: (1) giving and receiving help and (2) the way participants rely on each other's efforts, skills, knowledge, and concerns, as their primary source of help when sharing common life experiences and problems. The perceived benefits of support group participation on the learning and adaptation of the family carers are also consistent with the functional models of mutual aid groups, prevalent in the USA in the past decade. These models emphasise that inner-focused, therapeutic and supportive groups, comprising families of patients with chronic mental illness, strive to focus on providing personal growth opportunities for carers that promote individual change through empowerment and consciousness-raising goals. Such changes would include improvement in knowledge and skills regarding the mental illness and its care, carers being able to deal with their negative emotions concerning their patients and own self care, and improvements in seeking appropriate community support services (Heller et al., 1997b). These positive changes were identified as the benefits of group participation in this study.

9.3.4 Mechanism 4: Extending social support network both within and outside the support group



The final therapeutic mechanism of the mutual support group in this study was the extension of carers' social support network both inside and outside the support group. Section 9.2.2 discusses how the mutual support group in this study served three functional purposes of social support: (1) instrumental support, providing material aids and practical assistance with daily tasks; (2) information support, providing appropriate information and advice in caregiving; and (3) emotional support, conveying empathy, caring and trust to and from other group members. The importance of these functional dimensions for the family carers in the support group was reflected in the interview and group session data (see Section 8.4.2). Most carers indicated the unity and friendship as being similar to that of a close family member. Some family carers also offered to help other group members to manage their family affairs outside the group and, in this way, other members *became an additional important part of the family carers' social network.*

Though this sense of cohesiveness was strong among those family carers who had attended the group regularly and participated actively in the group activities, it was also closely linked to their altruistic behaviour towards other group members. Conversely, those carers who attended the group sessions inconsistently and infrequently, found that the demand to assist and take care of the concerns of others first, sometimes at the sacrifice of their own (i.e. altruism, as discussed in Section 9.3.1), overwhelmed them and made them question what benefits, if any, they were gaining from the group. This was consistent with recommendations by Wilson (1995) and Yalom (1995), who found that levels of cohesiveness and altruistic behaviour are essential factors if family carers are to benefit from their participation in the support group.

The results of this study demonstrate the truth of this by finding that the family carers who showed high levels of altruism towards, and cohesiveness with, other members in the support group, also reported greater and more substantial positive improvements in their psychosocial health condition over the 12-month follow-up period, compared with those who were not so closely linked with others in the group. It can be seen, therefore, that mutual support groups are able to create strong, cohesive forces while, at the same time, promoting attitudes of unselfishness and concern among participants and helping them to find value in helping resolve each other's problems and concerns before their

own. As discussed in Section 9.2.5, Chinese family carers of patients with schizophrenia in this study, who are already culturally inclined to accept these collective group and cohesive forces, find no problem in being receptive to the additional social support and practical assistance provided for them.

The findings of high levels of cohesiveness and openness in sharing their own experiences in this mutual support group raise two issues of cultural consideration in the family group work. First, the Chinese family carers who actively participated and openly discussed their own family situations in the support group were perceived as obtaining great benefit from their participation. These positive results are in contradiction to previous studies that tended to show that, culturally, Chinese people are passive and reserved when it comes to emotional and personal disclosure (Leung & Lee, 1996) and that a more directive and structured approach to their problems, conducted by the family therapist, was considered more productive (Wong & Chan, 1995). Second, the concept of 'gan qing' (emotional love), which symbolises mutual good feelings, empathy and friendship among Chinese people and is not easily found in Western people (Sun, 1991), might play an important role in the close supportive relationships of the support group participants in this study. Once this 'gan qing' has been cultivated and affirmed in a relational context by means of mutual aid and care, such as in this study, group members became highly inter-dependent and committed to helping one another.

The supportive environment outside a mutual support group is also an important factor in influencing the effect that such a support group has on its participants. Despite the strong cohesion and support among group members, it is also desirable for the family carers to have access to more links and interaction with health professionals and available community support services, thus enabling them to seek professional help and support independently when they need it. The family carers in the support group suggested that the group should be run as an adjunct to the local community mental health services, with all their aids, facilities and resources. All the carers had welcomed the participation and presentations by the health professionals who had attended at the request of the group.

Ample evidence indicates that the needs of families for professional support partly stems from their experiences of the stigma associated with mental illness (Rose, Mallinson & Walton-Moss, 2004). This stigma undermines any support that families might otherwise

have expected from their social and familial networks. Professional support can reduce these unmet needs of families caring for a mentally ill relative, because some families prefer to share their concerns with professionals as they feel they can rely on the professional conduct and expertise of clinicians, who understand their family situation and concerns, and will not violate their privacy. In spite of acknowledging the importance of professional support for these families, studies have confirmed that families do not receive adequate support from professionals (Solomon, 2000). Therefore, if the mutual support group can run in parallel with adequate support from health professionals, the effect of family intervention may be strengthened and thus the benefits to these families will be optimised.

However, this awareness of the need to obtain external support from health professionals among the families who participated in the support group may not necessarily increase their demands for health services. The findings of this and other studies on family intervention for patients with severe mental illness (Budd et al., 1998; Dyck et al., 2002) indicate that, through their group participation, family carers are better able to understand and select the services that they actually need and are most appropriate for them, as similar to the one reported by those in Section 7.4 (Chapter 7).

Moreover, more than half of the family carers in the support group in this study also indicated that the social support available from their family members and other people within their social networks, such as close friends and relatives, was another important element of support obtainable outside the support group and they considered this help equally important as the help they received from health professionals and the support group. With improved communication and interpersonal relationships with family members, as a result of their support group participation, family members and close friends can become the primary sources of immediate physical and emotional support for carers, when they are caring for patients and practising their newly learned caregiving skills.

The complementary interaction of three different sources of social support (family members, health professionals and support group members) further strengthens group participation and enhances its benefits for family carers, in addition to enhancing their ability to cope with the stress of caregiving. Mobilisation of adequate family support

resources (Langford et al., 1997; McCubbin & McCubbin, 1993), such as these, were perceived to be important to the family carers in this study, in acting as a protective buffer against the stress experienced by families in providing care for their patient.

The aims of this extended social support network within and outside the mutual support group was clear-cut from the later stage (fourth group stage) when the carers were eager to learn and adopt new roles and challenges in caregiving once they had understood their own and family needs. The carers felt that this stage of the support group was the *most rewarding stage of their group participation.* Most of them, in particular the novice carers, were able to learn and adopt new coping and caregiving skills, as well as effective communication with their patients and family members. Chou et al. (2002) suggested that these elements are the most important benefits of participation in the group, but the carers in this study also learned to undertake constructive activities with their ill relatives, such as participating in recreational activities organised by community centres.

The extension of the carers' social support networks was intensified in the final stage of the mutual support group, which, according to Powell (1994), has often been treated as relatively less important by group facilitators and participants, than the earlier phases of the group. The family carers also felt that the final meetings provided them with an opportunity to talk about their anxieties about leaving the group and to *plan for continued support and make arrangements for further, informal meetings and gatherings with other close group members* after the end of the group programme. Yalom (1995) suggested that the discussion and psychological preparation for separation from the other members is essential for helping group participants to feel secure about continued support in their future life and thus in relieving their anxieties.

In addition, the final phase was found useful for allowing the family carers to evaluate what they had learned during their group participation, as well as facilitating independence in their future family life. Weiss and Greene (1992) recommended that, through this evaluation and reflection on their learning in the last session, participants are able to consolidate their knowledge and skills learned in the group and have an opportunity to clarify any unclear concepts and misunderstandings. Before they left the group, arrangements were also made for future referrals to appropriate services, such as respite care, and when needed. Since so much importance was accorded to this period of

preparation and evaluation by five of the group participants in this study, when they requested an additional group session to discuss their learning and concerns, they were allowed to do so in accordance with the usual flexible approach of the support group.

CHAPTER 10 METHODOLOGICAL CRITIQUE

10.1 INTRODUCTION

This chapter reflects on the mixed research design selected to evaluate the process, context and outcomes of the group intervention used in this PhD study. It also provides a critique on the design and implementation of both the randomised controlled trial (RCT) and the qualitative approaches used in this study for the process evaluation of the group intervention.

10.2 THE USE OF MIXED METHODS FOR EVALUATION OF AN INTERVENTION – QUANTITATIVE & QUALITATIVE APPROACHES

Many researchers, particularly those conducting a health service evaluation research, advocate the use of more than one study method or approach to reach a comprehensive and clear understanding of the phenomenon to be evaluated. The Medical Research Council (1998) also recommends that evaluation of a complex health care intervention should involve a more holistic research approach. To determine whether the intervention works or not, quantitative measures should be used to identify the important health outcomes and the contextual and operational factors needed to optimise the intervention should be investigated. Mixed research methods might be more time consuming and increase the complexity of the study design. Nevertheless, different methods can be combined to good effect to address different questions concerning the therapeutic values of an intervention in terms of the process and context as well as the outcomes (Clark, 1998; Williamson, 2005). While the evaluative research in this thesis has not addressed all of the questions that Clark (1998), Williamson (2005) and other researchers have suggested should be posed for the evaluation of an intervention aimed at developing an innovative model of health care, it has covered many of the important issues.

Hanson et al. (2005) reviewed the studies in social sciences that used mixed methods design. They concluded that the collection or analysis of both quantitative and qualitative data in a single study might enrich the results in ways that would not be possible if only one of these types of data were used. Using both types of data, for example, allows researchers to simultaneously gain a deeper understanding of the phenomenon under study and to identify or modify the theoretical concepts in light of the feedback from participants. The precise, instrument-based measurements obtained

in an RCT may be augmented by contextual, field-based information obtained from the participants. Likewise, the qualitative findings may help the researchers to explain the negative results of the RCT at both the pragmatic and the theoretical levels. This reasoning underlay the decision to use both the RCT and the qualitative approaches to process evaluation of the group intervention in this study. The RCT used in this study evaluated the quantitative changes in the outcome measures for the family carers participating in the mutual support group. The qualitative approaches (interviews and recordings of all group sessions) revealed how the context and process of the support group were able to achieve the desirable changes for the families caring for a relative suffering from schizophrenia. In this way they contributed to a deeper understanding of both the RCT results and the therapeutic mechanisms of the intervention.

Psychosocial intervention is considered to be a complex social programme characterised by flexible and ambiguous protocols, service users with diverse health needs and concerns, and unclear external boundaries with uncontrollable interactions with the social environment (Wolff, 2001). Wolff commented that evaluation of these complex interventions should focus primarily on the pragmatic reasons for not restricting the evaluation to controlled trials only. Pragmatism draws on many ideas including using 'what works', using diverse research methods or approaches, and valuing both objective and subjective knowledge (Cherryholmes, 1992). For health services researchers, the use of both qualitative and quantitative approaches may be crucial to identify the potential interaction effects between the unmeasured social contexts, the intervention being tested and the outcomes for the participants. The process evaluation adopted for this thesis used a combination of qualitative approaches and the RCT and therefore has succeeded in identifying these interaction effects.

The mutual support group was set up to develop a peer-led programme reflecting the social context and forces in which it would be developed and operated. The group facilitator responded to the needs and demands of the group participants and the requirements of the intervention protocol, and used the skills he had learned at the training workshop for this study and during his previous experience of group interventions. This might result in the intervention being delivered in different ways to the three sub-groups, especially when the intervention protocol was not strictly adhered to and the content of each group session was flexible in order to reflect the preferences and common concerns of the participants. The personal characteristics of the facilitator and the social context within each sub-group would have a noticeable

impact on such a flexible group programme. Therefore, the use of qualitative approaches for formative evaluation in combination with an RCT for outcome evaluation is essential to determine the effectiveness of the mutual support group, including the possible reasons for its positive and negative results.

10.3 CRITIQUE OF THE RANDOMISED CONTROLLED TRIAL

A main part of the study described in this thesis was a randomised controlled trial (RCT) to study the effectiveness of a mutual support group programme conducted with Chinese family carers of people with schizophrenia. The aim of the RCT was to evaluate the effects of the group programme on a variety of psychosocial health outcomes in the patients and their families. For this clinical trial, which was similar to other psychosocial interventions, the mutual support group consisted of a group of family carers in their social environment. Its effects on the families were evaluated longitudinally over the 18-month study period, taking into account different unexpected and uncontrolled changes within the families, such as patient hospitalisation and other family events. These external and unexpected variables, which were generally beyond the control of the researcher (Matthews, 2000), might have had an influence on the study outcomes. As suggested by Wolff (2000), there are challenges and limitations to the use of the RCT for the evaluation of interventions in socially complex and largely non-standardised health services, and this may threaten the internal and external validity of the study. Some of the challenges were anticipated and taken into account when designing the trial, as described in Chapter 6 (Section 6.11).

The other main challenges (limitations) involved in conducting the RCT for the purposes of this thesis are described below. These limitations include: the flexible and dynamic intervention protocol and the subjectivity of the experimenter, the small-sized sample, excluding any co-morbidity with another mental illness, the participants' awareness (non-binding) of receiving the intervention, and their subjectivity in self-reported psychosocial outcomes and meaningful changes in functional state. They also include the attrition of participants, a few practical difficulties with the RCT, and the generalisability of the findings.

10.3.1 Flexible and dynamic intervention protocol and subjectivity of experimenter

Altman et al. (2001) pointed out that treatment protocols or guidelines reported in previous controlled trials and other intervention studies vary in their degree of clarity and comprehensiveness. In laboratory based or biochemical related trials, very concrete and strict protocols and procedures are crucial to minimise the risk of subjective measurement of the

outcomes, in order to ensure that the researchers' judgements do not bias the results of the trials. However, the mutual support group for family carers in this trial was a psychosocial intervention, which required protocols with a more flexible schedule. The social support and interpersonal interactions emphasised in the group programme were dynamic in nature. The procedures and progress of the intervention was therefore often subject to interpretation and adjustments made by the group participants and the group facilitator, even though the group facilitator and the researcher had already closely monitored these adjustments and continuously reviewed the adherence to the intervention protocol. In addition, the social interactions between any one family carer and the other carers and between the carers and the facilitator, and indeed how the group functioned, might have been stylised in part by the professional and personal characteristics of the facilitator and/or the researcher.

The protocol of the mutual support group designed by the researcher, together with the three-day training workshop for the group facilitator, and regular reviews of the group progress by the researcher (described in Chapter 4), helped to reduce the degree of ambiguity in the outcomes. They also increase the reliability of the measurement of the effect of the group intervention on the participants (Begg et al., 1996). However, the hard-to-model dynamic nature of the mutual support group intervention might make it difficult to ensure a high degree of standardisation and adherence to the intervention protocol evaluated in this trial, and thus reduce the internal validity of the study.

As described in Section 6.11 (Chapter 6), the personal characteristics of the group facilitator and the subjective biases of the researcher concerning the success of the group intervention is likely to affect the behaviour and performance of the subjects in the experimental and control groups (Yalom, 1995; Polit & Hungler, 1999). This could threaten the external validity of the results. In spite of the different time schedules for patients' follow-up visits in the outpatient clinics, it was not possible to completely avoid social interactions at the clinics between the family carers in the experimental and control groups. These social and information exchanges between the study subjects might also have influenced the treatment effects for the two study groups. In addition, there was the risk that the group facilitator and the researcher might have an emotional and intellectual interest in demonstrating the success of the intervention. This might be communicated unconsciously to the subjects or might lead to a bias in the observations and measurements, and so constitute a further threat to the external validity of the study (Polit & Hungler, 1999). Some measures were taken to minimise these threats. For example, the researcher, who was blind to the group allocation of the subjects, undertook all data collection, and the study subjects were asked not to inform other families or

staff in the clinics about their group participation. Nevertheless, the extent to which the researcher was blind to the allocation of families to the intervention and control groups was not tested. To test the success of blinding, the researcher could be asked to guess the group allocation of each family.

10.3.2 Small-sized sample excluding any co-morbidity with another mental illness

One aspect of the external validity of this trial concerned the adequacy of the sampling design. As suggested by Wolff (2000), creating a representative and equivalent sample for psychosocial intervention is often difficult for several reasons. First, the characteristics of study populations, such as multiple or co-morbid mental problems, are difficult to define precisely. Second, the eligible subjects targeted for the intervention may often be resistant or not motivated to accept the treatment and be difficult to engage, thus complicating the sample recruitment. Third, limited study sites and lack of access to potential study subjects may reduce the feasibility of random assignment. This study targeted only patients who were primarily diagnosed with schizophrenia, meeting the DSM-IV criteria and having no co-morbidity with other mental illness at the recruitment stage. The duration of their illness was also limited to not more than five years - the early or medium stage of the progress of schizophrenia. Despite the precise criteria (see Section 6.4.2) used to select the patients to be included in the sample for this study, these criteria might have excluded patients with psychiatric symptoms similar to schizophrenia, or those with dual psychiatric diagnoses or a longer duration of the illness. The cut-off point of five years for the duration of the illness excluded patients with more chronic schizophrenia or patients with dual diagnoses. This reduces the generalisability of the findings to the larger accessible population of Chinese patients with schizophrenia and co-morbidity with other mental health problems, and thus may reduce the external validity (Pharoah et al., 2001). In addition, since the small sample included only those families having relatives with schizophrenia living with them and attending two of the 16 psychiatric outpatient clinics in Hong Kong this might limit its ability to fully represent the total population of Chinese patients with schizophrenia.

Moreover, the study subjects were recruited from those families who were willing to participate. Their desire to participate may reflect only that they had more time and higher levels of motivation than those who declined to participate. Evidence for this is provided by the refusals to participate by some family carers on the grounds that they did not have sufficient time to attend a series of 12 group meetings. These carers emphasised that they had multiple roles within their family and thus additional family services might be needed to

relieve them and free them to participate in the mutual support group. In fact, the study subjects' strong desire to participate and cooperate in the intervention may account, in part, for its large effect. However, the nature of psychosocial interventions requires that the subjects are willing to participate, and so the controlled trial reflects the realities of clinical care.

10.3.3 Participants' awareness of receiving the intervention

As described in Section 6.11.3 (Chapter 6), the ideal of a double blind study could not be achieved due to the awareness of the subjects in the experimental and control groups about receiving the intervention and the study procedure (Bailer & Mosteller, 1992). By virtue of their group membership, those in the experimental group might perceive that they were receiving more care and attention than their counterparts in the control group. This might, in turn, affect their responses to the intervention and their scores on the measurement of the outcome. A related point is that some family carers in a group intervention may give socially desirable responses to the measurement of the outcome because they do not want to be perceived as difficult group members. The extent to which these factors may influence the responses of family carers to a group intervention, such as the mutual support group in this study, is not known.

10.3.4 Participants' subjectivity in self-reported outcomes and meaningful changes in functional state

In addition to those discussed above, three other important issues might have influenced the reliability and validity of the RCT used in this thesis. First, the data collected in this study were mainly concerned with the psychosocial conditions of families and patients, which were obtained from self-reports by the primary carers. Thus, these data reflected the subjective perceptions of the subjects, as opposed to the results of more objective methods such as observation of family daily behaviour and interactions. Inaccurate understanding or misinterpretation by the subjects of the items in the research instruments could lead to measurement errors. In addition, the effect of taking a pre-test on the participants' performance in the post-test, known as the testing effects, might have resulted in a sensitisation of the subjects in this study to issues that they had not contemplated before, such as the relationships between family members. As suggested by Matthews (2000), even though the use of a control group and a randomised sample could equalise part of its effects on the two study groups, the effects of the pre-test could not be segregated from those of the intervention (unless the Solomon four-group design had been used).

Second, the Chinese version of the primary outcome measure (family burden) was only translated and tested in the pilot study. Further testing of its psychometric properties should be conducted to ensure the validity and reliability of the instrument to be used in the Hong Kong Chinese population. The inter-rater reliability of the BPRS should also have been checked in the pilot or main study to ensure the accuracy in ratings of the patients' symptom severity by the attending psychiatrists.

Finally, the evaluation of a clinically significant change in psychosocial health status among recipients of a psychosocial intervention is a meaningful way of determining the practical importance of statistically significant differences between the groups under study. At the same time, it is important to understand the variability of psychosocial outcomes within a treatment condition (Tingey et al., 1996; Jacobson et al., 1997). However, limited RCT, experimental or quasi-experimental studies have been conducted to evaluate clinically significant changes in the participants' psychosocial condition as outcomes of an intervention. There are not any reference values for the clinically significant changes in the psychosocial outcome variables used in this study. The health status scales used in this study have been reported to have strong reliability and validity when used in previous psychometric testing. However, the clinical interpretation of their content, particularly their units of measurement, and the non-availability of a discrete cut-off point for normal functioning, are major limitations that need to be addressed to assess whether the clients reaching normal functioning could be used as the criterion for clinically significant change.

10.3.5 Attrition of participants

Mortality, which refers to the phenomenon of differential attrition from the groups being compared (Polit & Hungler, 1999), could have threatened the internal validity of this study. The attrition rates of the two study groups were exceptionally low in this study, largely as a result of the great efforts made by the group facilitator and/or the researcher to encourage and follow-up the participants. However, the variation in the attendance of the family carers in the support group (ranging from four to 12 sessions) might affect their involvement in the group and the possible benefits they might have obtained from their participation in the group.

Nevertheless, the data analysis for this trial had been designed on the intention-to-treat basis. Therefore, even if the subjects had attended only a few sessions, all group participants were used in the final analysis, with the exception of those who were withdrawn from the study before the pre-test test (Gibaldi & Sullivan, 1997). The statistically significant results of

the outcomes of the mutual support group, when compared with the control (standard care) group, could not reflect the variations of the treatment effect for individual group participants due to their different group attendance (treatment dose). This meant that some of the support group participants did not actually show significant improvements in their psychosocial health condition over the follow-up period. The findings on the families' clinically significant changes in the outcome measures (see Section 7.4.7) revealed that less than one-quarter (13% - 24%) of the group participants reported clinically significant changes in the families and patients' functional states one week after the group intervention. In addition, 5.3% to 15.8% and 5.4% - 13.2% of them at the second and third post-tests, respectively, reported unchanged or deteriorated psychosocial functions. Hence, it is noteworthy that group attendance by family carers may influence the benefits they gained from a mutual support group. This can vary according to a number of internal and external factors of the family carers such as their motivation and desire to participate, time availability and convenience, and the efforts of the group facilitator and/or researcher to encourage and remind them to attend the group sessions.

10.3.6 Practical difficulties with the RCT

The practical difficulties encountered in the RCT included the high workload of the facilitator, problems encountered in working out a sample frame, and changes in the social environment and community mental health practice over the study period.

High workload of the group facilitator

There was only one psychiatric nurse who was trained to be the facilitator of the mutual support group in this study. The facilitator was found to have a high workload in coordinating and monitoring the group progress and conducting bi-weekly follow-up of 38 families during the intervention period, and monthly follow-ups after completion of the group intervention. While having only one person implementing the intervention and providing the follow-up meant that there was consistency in the delivery of the intervention, the high workload and time limitation of the facilitator might also reduce the efficiency and quality of the intervention and follow-up care provided. Peer family carers in the mutual support group could have been invited to provide more assistance in coordinating the group sessions and establish more informal contacts with other group members to encourage their regular attendance.

Problems encountered in working a sample frame

The RCT included patients with short- and medium-term schizophrenia (i.e. duration of illness ranging from a few months to five years). About one-third of those on the patient lists (31%) had a record of irregular attendance or of default in the follow-up over a period of time at the outpatient clinics. The pilot study and previous experience of working in an outpatient clinic had indicated that it would be difficult with the manpower and resources available for this study to engage and follow up such patients and so they were not recruited for this trial. However, it is possible that the families of this group of patients who were not actively engaged with outpatient or community services, might in fact need more support and assistance from mental health services than those whose patients attended the clinic regularly. Such unmet needs for different family support services as well as a mutual support group were identified in a survey study of 200 families of outpatients with schizophrenia in the same geographical region in Hong Kong (Chien & Norman, 2003). On the other hand, it would have been very time consuming and highly labour intensive to work with this 'hard to engage' group. The cost of ensuring a high rate of attendance in the group by these families, and achieving a low attrition rate would have been very expensive. In addition, it was also impractical to follow up this group of families with only one facilitator available. As a result, the RCT involved only those patients who had irregular contact with outpatient services. It may not be possible, therefore, to generalise the results of this trial to 'hard to engage' patients.

The trial also involved only one primary carer from each family to participate in the mutual support group. This sample frame might influence the effect of the intervention on the families because if more than one member in each family had received the mutual support group intervention they could have offered each other mutual support and assistance in providing care for their mentally ill relative. In fact the majority of the patients in this study lived with two or more family members all of whom would inevitably be involved in caring for the patients. Their participation in future family group trials of this sort should be considered if they are available and willing to attend the group.

Changes in the social environment and community mental health practice

In implementing a clinical trial, it is important to ensure a similar treatment environment for both the experimental and the control group so as to ensure that any differences in outcomes between the study groups can be attributed to the intervention, rather than to other factors. However, the participants in this study were people who were living in a broader social context and so were influenced not only by the interventions but also by other

outside forces. Full control of the study environment, such as might be possible in a laboratory, could not be achieved. External events that take place concurrently with the mutual support group intervention might affect the study outcomes. These often occur when the intervention setting is within the larger social setting or the community. For example, apart from the group intervention, the participants' levels of family burden and functioning might also have been affected by psychosocial and instrumental support received from other family members, friends and health professionals, which were not controlled in this study.

As was the case for other longitudinal studies, there were also other changes in the family carers' condition and social environment, such as changes in the patient's treatment plan and mental health service policy. These might not be the same for the experimental and control groups over the 18-month study period. A shift to giving more emphasis to community-based mental health care in Hong Kong in the past three years has resulted in an increase in the availability of resources and financial support on developing various kinds of psychiatric rehabilitation programmes and expanding the community psychiatric nursing service. In fact the clinics did not provide any specific, structured intervention for the families of participants over the study period. Some of the extraneous variables, such as patients' mental condition, and participation in family therapies, were taken into account when analysing the study outcomes and by employing the randomised sampling method. However, other uncontrollable changes in the living conditions of the participants might still have had an influence on the study results.

10.3.7 Generalisability of the trial

Despite the random selection of the participants, most of the families in this study were volunteers and were highly motivated to participate in the group intervention, with very low dropout rates in the mutual support group. As already mentioned, the participants were chosen from the two outpatient clinics in one geographical region of Hong Kong. They were caring for only one adult family member (the patient) whose schizophrenia was of a short or medium duration (not more than five years of illness). This sample may not be representative of those with long-term schizophrenia, or of those with co-morbidity with other mental illnesses for which they were seeking and receiving mental health services. This highly selective sampling should be borne in mind when comparisons are made between this and other studies of family intervention. In addition, unlike the samples in many other Western studies on family intervention, it is important to note that nearly half of the patients in

this study were recruited when they were mentally stable and that about half of the family carers were male. These elements might affect the generalisation of the results of this trial to clinical practice.

The problem of the generalisability of the results of this study is also affected by changes in current local mental health practices and services, as mentioned in Section 10.3.5. There has been a trend for mental health services in Hong Kong to move towards community-based care since the year 2002. This has resulted in increased accessibility of different rehabilitation programmes and home visits by community psychiatric nurses, and might have had a positive impact on the family care of patients with schizophrenia in the community. In this way, the availability and variety of the usual family support services within the local mental health care system would be continuously improved. Consequently, the integration and implementation of the mutual support group tested in this study may have been affected by the changes in community-based care.

10.4 CRITIQUE OF THE QUALITATIVE APPROACHES

There is increasing use of qualitative methods for health care and nursing research to identify the important factors and internal mechanisms that influence a social phenomenon within a specific clinical setting or service. These factors or mechanisms can be explored by collecting the views and opinions of participants using different qualitative approaches such as interviews, observations and self-report diaries. To meet the needs of qualitative research, researchers have paid great attention to and been very concerned about ensuring the quality and trustworthiness of their research methods and strategies. Tuckett (2005) who reviewed Guba and Lincoln's (1989) trustworthiness criteria for qualitative research suggested a few important criteria for ensuring quality and rigour in qualitative research. These include: purposeful sampling and atypical cases, the researcher as instrument, respondent validation, and triangulation and clearly defined procedures. These criteria were adopted to critique the qualitative approaches (semi-structured interview and group session recording) used in this study and each is described below in turn.

10.4.1 Purposeful sampling and atypical cases

Purposeful sampling aims to include 'the widest possible range of information for inclusion in the thick description' of a phenomenon under investigation and, thus, facilitates transferability of the findings to the study population (Tuckett, 2005). This contributes to the credibility of the findings because the informants are sought out on

the grounds that they are likely to have and be able to share an understanding of the phenomenon. In this study, the researcher interviewed only 20 out of the 38 family carers who participated in the mutual support group. About half (47%) of the family carers refused to be interviewed, and so their perceptions and appraisal concerning the support group participation could not be included in the study. However, it is likely that data saturation had been reached because the last two interviews did not reveal any new codes and categories.

The sample should also be constructed to obtain information from the diverse perspectives of those involved in or affected by the support group. Interviews with the patients and/or other family members were necessary to explore their perceptions of the changes in the care provided by the carers following their group participation. The interview data would also reveal any improvements in the family condition and functional state. An interview with the facilitator was also necessary to generate useful data about his perception of the important issues raised by the intervention.

In addition, and as discussed in Section 9.4.2, the families were recruited from only two of the 16 psychiatric outpatient clinics available in Hong Kong and thus the results might not be fully representative of all family carers of outpatients with schizophrenia in the country.

The atypical (negative) cases can challenge the adequacy of the insights obtained, and in turn could assist the researcher to formulate more dependable and credible conclusions (Guba & Lincolin, 1989). All of the family carers in the mutual support group were invited for interview. The interviewees who accepted represented carers with different levels of improvement in their psychosocial health functioning, ranging from those who experienced statistically significant improvements to those experiencing a marked deterioration at the first post-test measurement. With both positive and negative cases identified in the interviews, the transcribed data revealed important information and an insight into the benefits and difficulties experienced by the family carers who participated in the group intervention.

10.4.2 The researcher as research instrument

The credibility of qualitative research resides in part in the skill and competence of the researcher. Semi-structured interviews with a tentative agenda were employed to ensure that some questions that were appropriate and important to the study objective (Objective 3 in Section 6.2.1) could be taken up with the family carers.

However, the open-ended method of interviewing meant inevitably that the more articulate relatives contributed substantially more to the data set than those who were less forthcoming with their views. The researcher also bore in mind that too much guidance or narrowly focused questions might restrict the thoughts and ideas of the interviewees and limit their free response to the topics of interest. An appropriate use of unstructured and guided questions by the interviewer to elicit in-depth and rich data from the respondents requires high levels of skills and experience in conducting qualitative interviews and it is often difficult to find such interviewers (Morse, 1997).

One of the potential biases that could be encountered when using qualitative research methods is the involvement of the researcher as the designer of the intervention, the interviewer of the participants, and the main person to undertake the data analysis. As a psychiatric nurse and educator with an enthusiasm for family-centred care of mentally ill patients, it is possible that the researcher would be eager to demonstrate that this family group programme could be useful and practiced in the community mental health setting. This potential bias could be minimised by comparing the qualitative data with the results of the RCT. In addition, the researcher was also keen to understand the difficulties experienced by the carers participating in the group and, thus, to identify the ways that the group programme could be improved.

It could also be argued that the researcher as the interviewer might influence the family carers (group participants) to produce socially desirable responses during the interview, and also that tape recording of the interviews could make the carers self-conscious and affect their responses to the interview questions. This was partially offset by giving a clear explanation to the interviewees of the purposes of the interview, the role of the researcher, and the reasons for making a tape recording. This potential problem was addressed by stating explicitly that it was important to learn from them about both the successful and the unsuccessful aspects of the intervention. They were assured that there would be no hard feelings on the part of the researcher (or the facilitator) if the discussion revealed where things had gone wrong in the group programme. Moreover, the researcher as an interviewer who understands clearly the purpose and design of the intervention could also help to ensure that the interviews remained focused on the objectives of the study. This could help to ensure that specific questions and issues concerning the family carer's experience and opinions regarding participation in the mutual support group, and the shortcomings of the intervention, could be discussed precisely and thoroughly.

Another potential source of bias was the researcher's involvement in the thematic data analysis. The data from the interviews and the group sessions were analysed by the researcher who might be expected to have a subjective bias concerning the positive effects of the mutual support group, and so might tend to distort the interpretation of the responses of the group participants. This potential bias was also minimised by involving a research assistant, who had not been involved in the intervention, to transcribe and code the data from the interviews and the group sessions independently, and to discuss with the researcher any differences in the transcription and coding.

10.4.3 Respondent validation

Respondent validation can serve a useful purpose to confirm or refute the meaning of the data or coding, for example 'sending it back' to the participants to ensure that what was understood was credible (Tuckett, 2005). Some researchers have argued that 'respondents are not always the best judge' of what counts for valid research (Sandelowski, 2002). The researcher took the view of Tuckett (2005), however, that the participants in this qualitative research needed to be able to recognise something of themselves and their world in the theorising if any claim for credibility was to be made. Disagreements between the researcher and the respondents about what happened should be identified and clarified before the final data analysis, to ensure that the actual meaning of the data reflected the respondents' subjective perceptions. Even though there were difficulties in engaging the family carers for a follow-up interview, four follow-up (second) interviews were carried out after the initial coding to clarify and interpret the difficulties the respondents had experienced in participating in the intervention.

However, it was impractical to apply the strategy of respondent validation to the data from the 12 group sessions. This is because it would be very hard to involve all of the 38 carers who participated in the intervention in the validation of the verbal interactions during the group sessions. It is very likely that the family carers would not be able to recall the meaning of each response given during each of the 12 two-hour group sessions.

10.4.4 Triangulation and clearly defined procedures

Methodological triangulation using dissimilar but complementary techniques for data collection, such as observation of participants' daily behaviour, field-notes of group meetings, participants' personal journals, and informal group discussion, could have been used to enhance the credibility and dependability of the findings (Miles & Huberman, 1994). It is because this would have permitted cross validation of data collected through different methods of data collection. In this study, however, only audio-taping of group sessions and individual interviews with the participants was used, in order to identify the similarities, consistency, or congruence of the perceived factors that contributed to the success or failure of the group programme. In addition, the audiotapes of the group sessions and interviews would not show the non-verbal behaviour of the participants, such as facial expressions, nodding and touching. This data collection method could produce enriched data on the feelings or perceptions of the respondents, and might be useful to confirm or refute the meaning of their verbal responses (Morse & Richards, 2002).

Tuckett (2005) also emphasised the need to clearly describe the data collection and data analysis procedures of qualitative research. In this thesis, these procedures were clearly explained in Chapter 6. A worked example of qualitative data analysis indicating the different steps in the six-stage procedure recommended by Miles and Huberman (1994) is attached in Appendix 11. Some extracts and verbatim notes from the interview and group session data were also used to illustrate the process of identifying, mapping, condensing and finalising the themes and categories.

Nevertheless, four therapeutic mechanisms were identified from the interview and group session data. These are only a few of the important components of mutual support groups for family carers, as elicited from the perception of half of the group participants (family carers) in this study. Further research should be conducted to validate these findings. More in-depth and accurate understanding of therapeutic mechanisms of a mutual support group for family carers of people with severe mental illness and family carers' difficulties experienced in group participation should be sought in larger and diverse samples of group participants, using methodological triangulations.

CHAPTER 11 CONCLUSIONS AND IMPLICATIONS

11.1 INTRODUCTION

This final chapter describes how this study adds to the knowledge of family intervention for people with schizophrenia (in Section 11.2). The chapter also discusses the implications of the findings from an evaluation of the effectiveness of the mutual support group programme for families of people with schizophrenia and the therapeutic mechanisms of the support group, for mental health services and research. Section 11.3 describes the implications for policy and clinical practice and Section 11.4 the implications for future research. Finally, Section 11.5 summarises the conclusions of the study as a whole.

11.2 CONTRIBUTION OF THE STUDY TO KNOWLEDGE

The study described in this thesis was the first randomised controlled trial (RCT) or research into the effectiveness of a mutual support group programme conducted among Chinese family carers of people with schizophrenia in Hong Kong. The design of this clinical trial was based on a critical review of the research undertaken during the past two decades, concerning mutual support groups and approaches to family intervention for patients with schizophrenia used in Chinese and Western countries (see Chapters 2 and 3). The findings of this study have increased our understanding of the effectiveness of a new model of family intervention for these patients. The design and methodology have also taken into account most of the methodological limitations described in the literature review of this thesis (see Section 2.5.5 in Chapter 2). The major contributions of this study to the knowledge of family intervention are described below.

11.2.1 The mutual support group is an effective alternative model of family intervention

The findings of this study provide evidence that the mutual support group, which had its origins in Western culture, can be an effective alternative model of family intervention for Chinese patients with schizophrenia. Recent reviews of clinical trials of family intervention (for example, Barbato & D'Avanzo, 2000; Pharoah et al., 2001) have highlighted a lack of consistent and conclusive evidence about the effects of family intervention on family-related health outcomes. However, by contrast, the

present study has found that family intervention was effective in improving the psychosocial functioning and state of health of both the patients and their entire family over a one-year follow-up period.

11.2.2 A simply structured supportive group environment and an empirically tested protocol will lead to an effective mutual support group

This study provides an insight into the design of family intervention for people with schizophrenia. The mutual support group used in this study was driven by a flexible, simple structure, and the recognition and resolution of common problems and concerns in caregiving by the group participants themselves. The positive findings of this study provide support for the proposition that to be effective a family intervention may not require strictly defined guidelines, a manual of intervention, and a set of advanced group conduction techniques, such as those used in a family psycho-education programme by Anderson et al. (1986) and a family behavioural management programme by Falloon (1985). Bringing family carers together in this flexible, mutual sharing and supportive intervention can produce goal-directed and beneficial effects for family carers by improving their psychological and social support and their ability to cope with the caregiving role.

The RCT provides health professionals with a research-based and empirically tested protocol for providing an effective multiple-family group intervention. According to previous experience of support group work (Wheelan, 1994; Kimberly, 1997), providing clear guidelines for a therapeutic group can enhance the development of the group and so promote the desired effects and outcomes. Ongoing review of the progress of the group, as was done by the group facilitator and the researcher in this study, can also ensure the adherence to and consistency of implementation of the protocol and thus enhance the integrity of the treatment.

11.2.3 The mutual support group intervention overcomes limitations of staff and resources

The use of a multiple-family group intervention, such as the mutual support group described in this study, may be one way of overcoming the limitations of staff and resources for individual family therapy that are the main barriers to the use of family intervention in routine practice (Fadden, 1997; Asen, 2002). The group facilitator of a mutual support group, as used in this study, only required three full days of training and a short period of supervision in practice. By contrast, other frequently

used models of family intervention for patients with schizophrenia, such as psycho-educational programmes and cognitive-behavioural therapy, require the group instructor to undergo at least one year of intensive training and supervised practice. The group facilitator in this study also experienced limited demand from the group participants for evening or weekend appointments, whereas most family programmes frequently involve a heavy demand for such work (Brooker, 2001). This was because the mutual support group participants in this study often sought help from the other group members, family members, close friends, and appropriate clinicians.

11.2.4 A clinically significant change in the health status of family carers

This study demonstrates the use of a statistical method suggested by Jacobson et al. (1999) to generate clinically meaningful results from measurement of the health status of family members, such as family burden and functioning. The clinically significant change in the direction of functionality used in this study may make it possible for the results to be translated into numerical quantities, and this in turn can facilitate comparisons with the benchmarks of changes (Tingey et al., 1996). This could provide a basis for deciding if a change in health status is clinically relevant.

11.2.5 The therapeutic mechanisms of the mutual support group

The four therapeutic mechanisms of the mutual support group intervention used in this study add to the knowledge about the therapeutic values of the different components of a mutual support group. They may also be applicable if this model is used in different patient populations and also to other models of family intervention. The three main themes, which reflected the changes in the family carers' perceptions and behaviour in the support group, were identified by the group participants themselves in the light of their perceptions of what were the most important benefits and difficulties experienced during their group participation. Among the identified themes and mechanisms, family education about the illness and its treatment, and the perception of the availability of adequate social support are shown to be the two most important and essential ingredients of the family mutual support model used in this thesis. These are believed to be the cornerstones of a mutual support group, and each can be shown to have a significant effect in isolation (Weiss & Greene, 1992; Winefield et al., 1998). A few strategies were adopted that increased the participation of the carers in the group and lowered the attrition rate in this study. These included

asking carers about their preferences and meeting these by allowing more flexibility in the timing or convenience of the scheduling of group sessions. Another strategy was to provide regular contact with and encouragement from the group facilitator and peer co-leader in between group meetings. The other mechanisms and themes included some that were similar to those perceived by other therapists and reported in previous studies. These included learning by analogy and identification of similar experience (Steinglass, 1998; Bishop et al., 2002), overcoming the social stigma attached to the illness (Asen, 2002), and creating adaptive patterns of coping with the illness and family life (Bishop et al., 2002). However, only limited research has been undertaken to investigate the potential therapeutic values of these components of a family mutual support group. Further research into the four therapeutic mechanisms as identified in this study may reveal some potential for developing a more consistent, reliable and effective family intervention programme for patients with schizophrenia.

11.2.6 Socio-cultural consideration of family intervention

Previous studies indicate that socio-cultural factors may influence the responses of family carers to different types of family intervention (Telles et al., 1995), but few conclusions have been reached about how to address this important issue. The design of the mutual support group programme used in this study has demonstrated the importance of considering the specific Chinese family culture and practices in Hong Kong. Some of the contents and issues discussed and practiced in the support group were designed to reflect the Chinese family's specific structure, relationships and communication patterns, and their attitudes towards mental illness. The feedback received from the family carers during the interviews and group sessions, as well as the positive outcomes of the intervention, demonstrate that the socio-cultural factors of family carers should be taken into consideration when designing a family intervention. In this way, the family needs that are specific to their own culture can be addressed. In addition, the findings of this study also demonstrate that mutual support group intervention can be effective in Chinese families of patients with schizophrenia, and this provides support for the idea that it can be effective across cultures.

11.2.7 Reduction of demand for community mental health services

The findings of this study also provide support for the claim that mutual support group intervention can reduce the demand of family carers for family support services (from M= 6.9 at baseline to M= 4.8 at one-year post-intervention) over a 12-

month follow-up period. This suggests that mutual support groups, if embedded in the usual outpatient services, will lead the family carers to be more discriminating in their help-seeking behaviour and increase their self-efficacy in caregiving, thus ensuring more appropriate and optimal utilisation of family services. This reduction in the need for services was not identified in other approaches to intervention shown in recent reviews of studies on family intervention (Pharoah et al., 2001; Pilling et al., 2002).

11.3 IMPLICATIONS FOR POLICY AND PRACTICE

The findings of this study provide evidence for the effectiveness of a family-oriented psychosocial intervention for patients with schizophrenia. Recommendations for service changes can be made based on the lessons to be drawn from the design, implementation and results of this service evaluation research. The following suggestions regarding the policy of community care and the practice of family intervention for patients with schizophrenia deserve particular attention:

1. Implications for the policy of community care for patients with schizophrenia;
2. Potential use of mutual support groups, particularly in Chinese populations;
3. Facilitation of a family carers group.

11.3.1 Implications for the policy of community care for patients with schizophrenia

The study described in this thesis was one of only a few pieces of research into the effectiveness of a mutual support group programme for Chinese family carers of people with schizophrenia. The RCT provides health professionals with a research-based and empirically tested protocol for providing an effective multiple-family group intervention. The policy of community care is based on the idea that family members will carry much of the responsibility for caring for their relative with schizophrenia. However, these families themselves need support. An effective model of family intervention, embedded in routine clinical practice, such as the mutual support group developed and evaluated in this study, can enhance the ability of the family carers to cope with the illness and the problems of caregiving by providing them with the necessary knowledge and skills.

The findings of this study also highlight three main implications for the policy on mental health care for patients with schizophrenia in Hong Kong. These are described below:

First, family oriented care of people with schizophrenia should be emphasised and embedded as part of standard outpatient care in the current policy of community care for people with mental illness in Hong Kong. For the community care of people with

schizophrenia in Hong Kong, in effect, family care is essential. Families need support, but where psychosocial or family intervention programmes do exist, they often pay little attention to addressing the health needs of the families. The findings of this study provide support for the effectiveness of mutual support group intervention as a model of family intervention, in terms of improvement in patients' functioning and reduction of length of their re-hospitalisation. In addition, a mutual support group can also promote the health of family carers and enhance the functioning of the whole family. This model of intervention can be conducted within the current standard outpatient service, to provide family-centred care of patients with schizophrenia.

Second, the mutual support group is a model of family intervention that would be more feasible and cost-effective to implement for mentally ill patients in the community than other family intervention programmes. The mutual support group in this study lasted about six months. This was much shorter in duration than other family intervention programmes which have been reported to be more effective than routine psychiatric care. Such programmes include, for example, a one-year behavioural family management by Randolph et al. (1994) in the USA, and a 24-month psycho-education programme by Xiong et al. (1994) in mainland China. In a similar way to other family support groups, when the mutual support group ends, families can continue to have informal contacts or meetings with other group members and easier access to appropriate services in case of further need. In addition, as demonstrated by the results of this study, mutual support group participants obtain support and care from other group members. This leads to a reduction in the demand for family support services following participation in a mutual support group.

Mutual support groups, like the one in this study, are often characterised by creative and interactive learning and flexible activities. The content of the group sessions is agreed by all of the group members. Such groups also require a relatively short period of training for the staff who will function as group facilitators, as compared with other family intervention programmes. The complex structure of the interventions, inadequately trained staff, and the intensive staff training and supervision required are major barriers to the implementation of family intervention in routine practice. The flexible family programme evaluated in this study does not suffer from these limitations since staff's training requirements are minimal.

Third, extension of the dissemination of mutual support groups would require more than simply providing effective training for nurses or competent delivery of the intervention. It is probable that some reorganisation of the service aims and practices would also be necessary if this support group, or other family group work, is to be given high priority in community

mental health services in Hong Kong, as well as in Asian and Western countries. It would also involve providing nurses and other health professionals with the time and resources to work through the intervention. As suggested by Corrigan and McCracken (1995), dissemination of a novel intervention into routine practice is more likely to succeed through the use of a strategy designed to change the practice of the whole working team rather than that of individual clinicians. For this reason, how family mutual support group intervention can be applied to the care of patients with schizophrenia should be fully explained to mental health professionals at all levels, and the skills needed for support group facilitation should also be fully imparted to them. This can increase their awareness that such an intervention could achieve the prized goals of patient treatment as well as promotion of the family's health.

11.3.2 Potential use of mutual support groups, particularly in Chinese populations

The findings of this study support the use of mutual support group intervention for family carers of a relative with schizophrenia in a Chinese community, facilitated and followed up by a registered psychiatric nurse with adequate training of group facilitation techniques. There are five main implications for clinical practice. They include the following.

First, nurses and other healthcare professionals should recognise the potential efficacy of mutual support group intervention for Chinese families of people with schizophrenia and implement it as a family-oriented psychosocial intervention. The mutual support group specifically designed for Chinese family carers in this study demonstrated its effectiveness in reducing the psychological distress and burden of the families, and the patients' re-hospitalisation. In other words, it improved family and patient functioning, but without increasing the demand for community mental health services. Given the current limited understanding of what would be an effective model of family intervention appropriate to Chinese culture, this study provides evidence that a mutual support group can be potentially effective in Chinese populations. In particular, it addresses family needs in the context of Chinese culture, such as the interdependence amongst family members and the emphasis on practical assistance. The group programme and its intervention protocol can be used by nurses and other health professionals to provide family-centred mental health care to patients with schizophrenia, in addition to the use of psychotropic medication and other usual forms of care.

Second, the findings indicate five characteristics of an effective family mutual support group for schizophrenia, which should be considered in future family group work. These include:

- The therapist/facilitator engages the family in a collaborative working relationship, which encourages family members to participate actively in identifying and resolving their own problems;
- Adequate information is provided for family carers concerning the symptoms and treatment of schizophrenia, and the effects of psychosocial stressors on the course of the illness;
- Clear and measurable common goals and tasks of the family group are formulated and agreed by group participants; and the progress of the individual and group development is regularly reviewed by the group facilitator and health care team;
- There is a systematic appraisal of the clinical and social needs of both patients and their carers using valid and reliable measures; and
- Strategies are employed to achieve effective caregiving and problem resolution, such as improving family communications and relationships, enhancing the skills of the carer in problem solving and coping with caregiving, and minimising negative emotional reactions to the illness. These strategies are designed to increase mutual support, trust and concern among the group participants.

These characteristics were also reported in previous published studies on mutual support groups and other approaches to family intervention (Leff, 1994; Pharoah et al., 2001). They are found to be important for achieving significant improvements in health outcomes for patients and their families, such as those reported in this study.

Third, the four therapeutic mechanisms and the three negative factors identified from the data drawn from the interviews and group sessions contain important information to be taken into consideration by health professionals when designing family groups for patients with schizophrenia. The therapeutic mechanisms highlight the important elements of a family group. These consist of the reconstruction of the role identity and concepts of caregiving of the carers, the essence of psychological empowerment through the acquisition of knowledge and skills, establishing and focusing on realistic common goals, regular attendance and active participation in the group activities, and extending the social support networks both within and outside the group. The three negative factors, such as dominant and forceful behaviour by some group members, which creates barriers to carer participation in the support group, should also be given particular attention.

Service users of family intervention, such as the family carers of patients with schizophrenia in this study, have a unique perspective on mental health care but their views are seldom sought (Clifford et al., 1991). The findings of this study concerning the perceived

benefits and difficulties of mutual support group participation are tentative, but they do point to some potential ways of increasing the understanding of the therapeutic components of a mutual support group for families of patients with schizophrenia. As evidenced by the perceptions of the family carers of the importance of, and difficulties experienced in, participation in the support group, these results contribute to our understanding of the important factors influencing the social interactions and development, and possibly the therapeutic outcomes, of a mutual support group for families of patients with schizophrenia in a Chinese population. These findings also provide an insight for clinicians and researchers into the therapeutic components of family intervention for people with schizophrenia. These are still relatively disregarded in current research and routine practice and thus their adoption could produce great benefits for family carers.

Fourth, the introduction of the family intervention protocol and facilitator training workshop in this study involved an explicit formal entitlement to family intervention as well as mutual support group intervention. It also provides service managers and clinicians with guidance on how to implement a multiple-family group intervention, which can be specifically designed to be effective for Chinese patients. As the group programme is implemented as a part of the routine day-to-day practice in mental health services, its protocol and health outcomes can easily be monitored by health professionals (such as a group facilitator or service manager). This would make it possible for the effectiveness of the service to be audited.

Fifth, additional individual support and group sessions may be necessary to optimise the effect of the support group intervention on family carers. As indicated by the interviews and group session data analysed in this study, some family carers had some difficulty in building trust and in openly sharing their caregiving situation. Such carers may need individualised assessment of their psychosocial needs at an early stage in the group intervention. If they are given particular support and concern by the group facilitator and the other group members, these family carers can develop trust, mutual respect and understanding with the members of the support group.

Additional group sessions can be arranged after the closure of the support group if requested by the participants. These additional sessions can reinforce the support for the family carers and, thus, are important in maintaining the treatment effects over time (Dixon et al., 1999). Continuation of the support group, self-administered by family carers, can also serve a similar purpose of maintaining the mutual support amongst group members. Thus, the group facilitator may consider arranging booster group sessions to support the further development of

family carers and maintain the improvement in their psychosocial health state as they continue to perform their caregiving role. The values of such booster sessions and their benefits for participants have been suggested in the literature on family intervention (Bae & Kung, 2000).

In sum, mutual support group intervention is potentially effective in Chinese families of patients with schizophrenia, as demonstrated in this evaluation research. Mental health professionals and policy makers might consider using this model of family intervention in combination with other medical and psychosocial treatment in routine practice, to optimise the patients' psychiatric rehabilitation in the community. However, more research should be conducted to support the use of this type of intervention for Chinese families with different socio-demographic backgrounds.

11.3.3 Implications for facilitation of a family carers group

The role of the group facilitator in the mutual support group programme, and potential obstacles to the development of the group, were also taken into consideration when designing the intervention and were clearly specified in the intervention protocol (see Sections 4.3 and 4.10.2 in Chapter 4). The 3-day training workshop (see Section 4.5) was able to adequately prepare the group facilitator to assist individual group participants in their adaptation and learning in the support group, as well as the development of the group as a whole. On this basis, the group facilitation described in this study worked well and the feedback from the family carers in the support group concerning the group facilitation was mainly positive. However, a few recommendations can be made about the facilitation aspect:

- A treatment protocol and training for group facilitation is essential, even though they are minimal when compared with other approaches to family intervention. Supportive supervision (by group organisers or researchers) can help to guide the facilitator, including early intervention to deal with his/her personal biases and any difficulties encountered in the group facilitation process.
- It is helpful if the facilitator in a mutual support group has some experience, basic knowledge and skills in family group work. These can include such qualities as understanding the illness and its treatment and the available community services, good interpersonal and communication skills, and an empathetic and caring attitude to the situation of family members involved in caregiving as well as their health needs.
- The facilitator, together with his/her team in a family group intervention, should conduct an ongoing review of the group progress. Discussion and reflection is needed to deal with

unexpected problems, help find solutions and suggest ways to improve the development of the family group.

- It is important for the facilitator to follow up group participants between group meetings. Regular contacts and interaction with group participants can provide a better understanding of their health needs, identify immediate problems, and monitor the progress of the group.

The first recommendations are in line with what other researchers have suggested (Galinsky & Schopler, 1995; McFarlane, 2002). However, the need for a regular review of progress and follow-up by the facilitator and his/her team during the group intervention has not been widely covered in the literature on family group intervention. Group facilitation should focus not only on assisting and encouraging change through personal growth and the interactive group forces during group sessions, but also on an ongoing evaluation of and reflection on the progress of the group in order to enhance its development (Moos et al., 1993).

11.4 IMPLICATIONS FOR FUTURE RESEARCH

This study describes the positive effects of a mutual support group intervention for families of people with schizophrenia with respect to their psychosocial functioning and other health outcomes. However, the results of this study, although promising, may not be generalisable to other Chinese populations of families with a relative with schizophrenia living in the community. Further clinical trials should be undertaken, therefore, covering larger diverse samples of Chinese family carers drawn from different socio-economic and cultural backgrounds. These trials should also include people with chronic schizophrenia and with co-morbidity of other mental illnesses. Such clinical trials are needed to confirm that mutual support group intervention has the potential to prevent or substantially reduce the stress of family caregiving for people primarily diagnosed with schizophrenia.

In addition, it is recommended that clinical trials be undertaken to compare the mutual support group programme used in this study with other widely accepted models of family intervention for patients with schizophrenia, such as cognitive-behavioural and psycho-education group programmes, to assess their relative effectiveness for families and for their patients' psychosocial health outcomes. In this way, the relative effectiveness of different modalities of family intervention for Chinese patients with schizophrenia, which are unknown at present, can be evaluated.

In this study, a small convenience sample (n= 20) was available for interview, consisting of almost half of the 38 participants in the support group. For this reason, the perceptions reported may not be fully representative of the views of all participants of the mutual support group investigated in the study, mutual support groups generally, or of those involved in other family intervention programmes. As suggested by Maton (1993), a more comprehensive and in-depth understanding of the group process, in terms of the group integrity and development, the participants' level of involvement and the appraisal of group participation, is essential to understand the therapeutic mechanisms of a mutual support group.

The four therapeutic mechanisms of the mutual support group identified in this study need to be further tested with more diverse family groups, from different socio-economic and cultural backgrounds, drawn both from within the Chinese population and across cultures. More rigorous qualitative studies are required of the family carers' perceptions of the therapeutic components of a mutual support group. Such studies may possibly involve methods other than interviews and the triangulation of methods or data, such as observation and self-report diaries. These methods may elicit a broader range of data from the group participants (family carers) both during and outside group meetings and provide increased understanding of the home practices and family situations between group sessions. These data would be useful to reveal a more comprehensive picture of the group progress and the personal development of family carers. In addition, these data may possibly reveal other important factors or a different model of therapeutic mechanisms that influence the success of a mutual support group for family carers. The relationships between family carers and other people in their social networks, such as family members, friends and health professionals, should be investigated. This could provide a better understanding of the carers' perceptions of social support outside a support group, as well as its influence on their attendance and the benefits they consider they have gained from participation in the group.

As schizophrenia is a severe and enduring mental illness, family carers may often provide care for patients over a long period of time. It follows, then, that psychosocial interventions for family carers should be targeted at providing not only an immediate and strong positive impact but also a sustained positive effect in the longer term. This study investigated the effect of a mutual support group over only one year following the completion of the intervention. Further research should seek to

evaluate the longer-term effects of mutual support group intervention (for example, over two years) using multiple outcome measures for family carers and their patients.

Moreover, whilst professional support and the continuation of supportive sub-groups might in effect serve as a booster, there were no formal booster sessions of the group over the 12-month follow-up period of this study. The boosting of support for family carers after completion of the family intervention, for example by holding a few additional group sessions, may be important in maintaining the health promoting effect of the intervention (Dixon et al., 1999), and this should be considered and also evaluated in future research.

The participants in this study included only those who were willing and free to participate. Their desire to participate and cooperate in the intervention may account, in part, for its large effect. The degree of group involvement, the support received and given during and outside group meetings, and social contacts outside the group meetings can be major predictors of the psychological, social and information benefits of mutual support groups for family carers (Ustun, 1999). However, it was not feasible to examine these in this study. Further research into these contributing factors and their association with the effectiveness of a mutual support group is warranted.

Finally, the positive findings of the study with respect to family functioning suggests that more research is necessary to investigate the relationships between family conflicts, psychological distress and coping strategies among Chinese family carers and different cultural groups.

11.5 CONCLUSIONS OF THE STUDY

The family mutual support group intervention examined in this randomised controlled trial had, overall, substantial positive effects on the psychosocial well being of the family carers and of their patients with schizophrenia, as well as on the functioning of the entire family. The majority of the families in the mutual support group also demonstrated clinically significant changes in their functional states at the 12-month follow-up stage. In the light of these significant positive findings, the application and further testing of mutual support groups for families of people with schizophrenia in the context of the mental health services in a locality is recommended.

The findings in this thesis are in line with the suggestions contained in the literature on family intervention studies that the treatment of the family carers may be an important component of a comprehensive treatment for schizophrenia and other chronic and severe

mental illnesses. Interventions that have demonstrated efficacy, such as the mutual support group evaluated in this study, should be tested more widely. Such tests should take place in different community settings in diverse ethnic groups, and covering different geographic settings, illness entities and caregiver types, in order to more fully evaluate their generalisability and their effects on the health outcomes for both the patients and their families.

Few techniques of measuring the burden of the family caregiver have been validated for use with Asian populations. The Family Burden Interview Schedule was translated into the Chinese language for this study. The findings of the psychometric properties of this Chinese version established its potential as a research instrument for measuring the family burden of Chinese patients with schizophrenia, for example, for examining the outcomes of a family intervention.

The findings of the thematic analysis of the interview and group session data do provide insights for clinicians and researchers into the therapeutic mechanisms of family intervention for patients with schizophrenia, which are still relatively disregarded in research and routine practice. Service users of psychosocial interventions have a unique perspective on mental health care but their views are seldom sought. These findings also increase our understanding of the benefits and inhibiting factors that influence the social interactions and development of a mutual support group, as perceived by the group participants themselves. Mental health professionals could take these elements into account when they design psychosocial interventions, in order to produce the greatest benefits for family carers and their patients.

This evaluation study adds to the knowledge of the design and implementation of a potentially effective model of family intervention for people with schizophrenia, particularly in Chinese populations, and determined the immediate and significant outcomes for the psychosocial health conditions of both family carers and patients. The formative and process elements of the evaluation in this study, using interviews and tape-recordings of all group sessions, also provide information on how the mutual support group worked, in order to improve the intervention. Hence, this evaluation research can provide information about the effects and the processes by which a mutual support group programme could become an innovative model for family intervention for Chinese families of a relative with schizophrenia in Hong Kong. This knowledge may also be applied and tested in other models of family intervention, as well as in family programmes within diverse clinical settings or patient populations.

REFERENCES

Abramowitz, I.A. & Coursey, R.D. (1989) Impact of an educational support group on family participants who take care of their schizophrenic relatives. **Journal of Consulting & Clinical Psychology**, 57(2) April, pp.232-236.

Adams, C.E., Duggan, L., Wahlbeck, K. and White, P. eds. (1998) **Schizophrenia module of the Cochrane Database of Systematic Reviews.** The Cochrane Collaboration, Issue 1. Oxford, The Cochrane Library.

Adamsen, L. (2002) From victim to agent: the clinical and social significance of self-help group participation for people with life-threatening diseases. **Scandinavica Journal of Caring Science**, 16 (3), pp.224-231.

Akinson, J.M. & Coia, D.A. (1995) **Families coping with schizophrenia: a practitioner's guide to family groups**. New York, John Wiley & Sons.

Altman, D.G., Schultz, K.F., Moher, D., Egger, M., Davidoff, F., Elbourne, D., Cotzsche, P.C. & Lang, T. (2001) The revised CONSORT statement for reporting randomized trials: explanation and elaboration. **Annals of Internal Medicine**, 134 (8) April, pp.663-694.

American Psychiatric Association. (1994) **Diagnostic and statistical manual of mental disorders**. 4th ed. Washington, DC, American Psychiatric Association.

American Psychiatric Association. (1997) Practice guidelines for the treatment of patients with schizophrenia. **American Journal of Psychiatry**, 154 (Suppl), pp.8-80.

Anderson, C., Reiss, D. & Hogarty, G. (1986) **Schizophrenia and the family: a practitioner's guide to psychoeducation and management**. New York: Guilford Press.

Anderson, J. & Adams, C. (1996) Family interventions in schizophrenia: an effective but underused treatment. **British Medical Journal,** 313 (7056) August, pp.505-506.

Antze, P.A. (1979) The role of ideologies in peer psychotherapy groups. In: Lieberman, M.A. & Borman, L. eds. **Self-help groups for coping with crisis.** San Francisco, Jossey-Bass. pp.272-304.

Arno, P.S., Levine, C. & Memmott, M.M. (1999) The economic value of informal caregiving. **Health Affairs**, 18, pp.182-188.

Asen, E. (2002) Multiple family therapy: an overview. **Journal of Family Therapy**, 24, pp.3-16.

Bae, S.W. & Kung, W.W.M. (2000) Family intervention for Asian Americans with a schizophrenic patient in the family. **American Journal of Orthopsychiatry**, 70 (4) October, pp.532–541.

Bailer, J.C. & Mosteller, F. eds. (1992) **Medical uses of statistics**. 2nd ed. Boston, MA, NEJM Books. pp.333-347.

Bandura, A. (1977) **Social learning theory**. Englewood Cliffs, NJ, Prentice Hall.

Barbato, A. (1998) **Schizophrenia and public health.** Geneva, Division of Mental Health & Substance Abuse, World Health Organisation.

Barbato, A. & D'Avanzo, B. (2000) Family interventions in schizophrenia and related disorders: a critical review of clinical trials. **Acta Psychiatrica Scandinavica**, 102 (2) August, pp.81-97.

Barne, J., Stein, A. & Rosenberg, W. (1999) Evidence based medicine and evaluation of mental health services: methodological issues and future directions. **Archives of Diseases in Childhood**, 80 (3) March, pp.280-285.

Barnes, T.R.E., Hutton, S.B., Chapman, M.J., Mutsatsa, S., Puri, B.K. & Joyce, E.M. (2000) West London first episode study of schizophrenia: clinical correlates of duration of untreated psychosis. **British Journal of Psychiatry,** 177 September, pp.207-211.

Barrowclough, C. & Johnston, M. (1996) Distress, expressed emotion and attributions in relatives of schizophrenic patients. **Schizophrenia Bulletin,** 22 (4), pp.691-702.

Barrowclough, C., Marshall, M., Lockwood, A., Quinn, J. & Sellwood, W. (1998) Assessing relatives' needs for psychosocial interventions in schizophrenia: a relatives' version of the cardinal Needs Schedule (RCNS). **Psychological Medicine**, 28 (3) May, pp.531-542.

Barrowclough, C., & Parle, M. (1997) Appraisal, psychological adjustment and expressed emotion in relatives of patients suffering from schizophrenia. **British Journal of Psychiatry**, 171 (1) July, pp.26-30.

Barrowclough, C. & Tarrier, N. (1992) **Families of schizophrenic patients: cognitive behavioural intervention.** London, Chapman & Hall.

Barrowclough, C., Tarrier, N., Lewis, S., Sellwood, W., Mainwaring, J., Quinn, J. & Hamlin, C. (1999) Randomised controlled effectiveness trial of a needs-based psychosocial intervention service for carers of people with schizophrenia. **British Journal of Psychiatry,** 174 (6) June, pp.505-511.

Bateson, D.H., Jackson, D., Haley, J. & Weakland, J. (1956) Towards a theory of schizophrenia. **Behavioral Science**, 1, pp.251-264.

Battaglino, L. (1987) Family empowerment through self-help groups. In: Hatfield, A.B. ed. **Families of the mentally ill: meeting the challenges.** New Directions for Mental Health Services, No. 34. San Francisco, Jossey-Bass. pp.43-52.

Bebbington, P. & Kuipers, L. (1994) The predictive utility of expressed emotion in schizophrenia: an aggregate analysis. **Psychological Medicine**, 24 (3) August, pp.707-718.

Begg, C., Cho, M., Eastwood, S., Horton, R., Moher, D., Olkin, I., Pitkin, R., Rennie, D., Schulz, K.F., Simel, D. & Stroup, D.F. (1996) Improving the quality of reporting randomized controlled trials. The CONSORT statement. **Journal of American Medical Association**, 276 (8) August, pp.637-639.

Becker, T., Leese, M., Clarkson, P., Taylor, R.E., Turner, D., Kleckham, J. & Thornicroft, G. (1998) Links between social network and quality of life: an epidemiologically representative study of psychotic patients in south London. **Social Psychiatry & Psychiatric Epidemiology**, 33 (7) July, pp.229-304.

Bellack, A.S., Haas, G.L., Scholloer, N.R. & Flory, J.D. (2000) Effects of behavioural family management on family communication and patient outcomes in schizophrenia. **British Journal of Psychiatry**, 177 November, pp.434-439.

Bellack, A.S. & Mueser, K.T. (1993) Psychosocial treatment for schizophrenia. **Schizophrenia Bulletin**, 19 (2), pp.317-336.

Bentall, R.P., Haddock, G. & Slade, P.D. (1994) Cognitive therapy for persistent auditory hallucinations: from theory to therapy. **Behaviour Therapy**, 25 (1) Winter, pp.51-66.

Berbrier, M. & Schulte, A. (2000) Binding and nonbinding integration: the relational costs and rewards of social ties on mental health. **Research in Community and Mental Health**, 11, pp.3-27.

Berglund, N., Vahlne, J.O. & Edman, A. (2003) Family intervention in schizophrenia: impact on family burden and attitude. **Social Psychiatry and Psychiatric Epidemiology**, 38 (3) March, pp.116-121.

Berkman, L.F. & Glass, T. (2000) Social integration, social networks, social support, and health. In: Berkman, L.F. & Kawachi, I., eds. **Social epidemiology**. New York, Oxford University Press. pp.137-173.

Bernheim, K. (1982) Supportive family counselling. **Schizophrenia Bulletin**, 8 (4), pp.634-648.

Bernheim, K.F. & Lehman, A.F. (1985) **Working with families of the mentally ill**. New York, Norton.

Bernheim, K.F. (1987) Psychologists and families of the severely mentally ill: the role of family consultation. **American Psychologist**, 44 (3) March, pp.561-564.

Bezchlibnyk-Butler, K.Z. & Jeffries, J.J. (1998) **Clinical handbook of psychotropic drugs.** 8th edition. Seattle, Hogrefe and Huber.

Biegel, D.E., Robinson, E.A. & Kennedy, M.J. (2000) A review of empirical studies of interventions for families of persons with mental illness. **Research in Community and Mental Health**, 11, pp.97-130.

Biegel, D.E., Shafran, R.D. & Johnsen, J.A. (2004) Facilitators and barriers to support group participation for family caregivers of adults with mental illness. **Community Mental Health Journal**, 40 (2) April, pp.151-166.

Billings, A.G. & Moos, R.H. (1985) Life stressors and social resources affect post-treatment outcomes among depressed patients. **Journal of Abnormal Psychology**, 94, pp.140-153.

Billings, J.R. (2000) Community development: a critical review of approaches to evaluation. **Journal of Advanced Nursing**, 31 (2), pp.472-480.

Birchwood, M. (1996) Early intervention in psychotic relapse. In: Haddock, G. & Slade, P. eds. **Cognitive-behavioural interventions for psychotic disorders**. London, Routledge. pp.94-106.

Birchwood, M., McMillan, F. & Smith, J. (1992) Early signs of relapse in schizophrenia: maintaining methodology. In Kavanagh, D. ed. **Schizophrenia: an interdisciplinary handbook**. London, Chapman and Hall, pp.189-200.

Birchwood, M. & Smith, J. (1991) **Understanding schizophrenia.** Birmingham, Bromsgrove & Redditch Health Authority.

Bishop, P., Clilverd, A., Cooklin, A. & Hunt, U. (2002) Mental health matters: a multi-family framework for mental health intervention. **Journal of Family Therapy**, 24, pp.31-45.

Bland, R. & Darlington, Y. (2002) The nature and sources of hope: perspectives of family caregivers of people with serious mental illness. **Perspectives of Psychiatric care**, 38, pp.61-68.

Bogat, G.A., Sullivan, L. A. & Grober, J. (1993) Applications of social support to preventive interventions. In: Glenwick, D.S. & Jason, L.A. eds. **Promoting health and mental health in children, youth, and families**. New York, Springer. pp.102-158.

Borkman, T.J. (1984) Strengthening the selectively unsupportive personal and community networks of their members. In: Gartner, A. & Riessman, F. eds. **The self-help revolution**. New York, Human Sciences Press. pp.205-216.

Borkman, T.J. (1999) **Understanding self-help/mutual aid: experiential learning in the commons.** New Brunswick, NJ, Rutgers University Press.

Bracken, B.A. & Barona, A. (1991) State of the art procedures for translating, validating and using psychoeducational tests in cross-cultural assessment. **School Psychology International**, 12 (1) February, pp.119-132.

Brady, C.F., Goldman, C.R. & Wandersman, A. (1994) Similarities and differences in caregiver adaptation: focus on mental illness and brain injury. **Psychosocial Rehabilitation Journal**, 18 (1) July, pp.35-48.

Brink, P.J. & Wood, M.J. (1998) **Advanced design in nursing research**. 2nd ed. Thousand Oaks, CA, Sage Publications.

Brissette, I., Cohen, S. & Seeman, T.E. (2000) Measuring social integration and social networks. In: Cohen, S., Underwood, L. & Gottlieb, B. eds. **Measuring and intervening in social support. New York, Oxford University Press**. pp.53-85.

Brooker, C. (1990) Expressed emotion and psychosocial intervention: a review. **International Journal of Nursing Studies,** 27 (3), pp.277-285.

Brooker, C. (2001) Decade of evidence-based training for work with people with serious mental health problems: progress in the development of psychosocial interventions. **Journal of Mental Health**, 10, pp.17-31.

Brown, G.W., Monick, E.M., Carstairs, G.M. & Wing, J.K. (1962) Influence of family life on the course of schizophrenia illness. **British Journal of Preventive Social Medicine**, 16, pp.55-68.

Buchkremer, G., Schulze, M.H., Monking, H., Holle, R. & Hornung, W.P. (1995) The impact of therapeutic relatives' group on the course of illness of schizophrenic patients. **European Psychiatry,** 10 (1), pp.17-27.

Budd, R.J. & Hughes, I.C.T. (1997) What do relatives of people with schizophrenia find helpful about family intervention? **Schizophrenia Bulletin,** 23 (2), pp.341-347.

Budd, R.J., Oles, G. & Hughes, I.C.T. (1998) The relationship between coping style and burden in the carers of relatives with schizophrenia. **Acta Psychiatrica Scandinavica**, 98, pp.304-309.

Burland, J. (1998) Family-to-family: a trauma-and-recovery model of family education. In: Lefley, H. ed. **Family coping with mental illness: the cultural context.** San Francisco, CA, Jossey-Boss Publishers: pp.33-41.

Bustillo, J.R., Lauriello, J., Horan, W.P. & Keith, S.J. (2001) The psychosocial treatment of schizophrenia: an update. **American Journal of Psychiatry**, 158 (2) February, pp.163-175.

Butzlaff, R.L. & Hooley, J.M. (1998) Expressed emotion and psychiatric relapse: a meta-analysis. **Archives of General Psychiatry,** 55 (6) June, pp.547-552.

Cacioppo, J.T., Hawkley, L.C., Crawford, E., Ernst, J.M., Burleson, M.H. & Kowalewski, R.B. (2002) Loneliness and health: potential mechanisms. **Psychosomatic Medicine**, 64, pp.407-417.

Canavan, J. (2000) The role of the family in schizophrenia. **Trinity Student Medical Journal**, 1 May, pp.31-39.

Canive, J.M., Sanz-Fuentenebro, J., Vazquez, C., Qualls, C., Fuentenebro, F., Perez, I.G. & Tuason, V.B. (1996) Family psychoeducational support groups in Spain: parents' distress and burden at nine-month follow-up. **Annuals of Clinical Psychiatry**, 8 (2) June, pp.71-79.

Caprara, G.V. & Steca, P. (2005) Affective and social self-regulatory efficacy beliefs as determinants of positive thinking and happiness. **European Psychologist**, 10 (4), pp.275-286.

Carpenter, J.S. (1997) Self-esteem and well-being among women with breast cancer and women in an age-matched comparison group. **Journal of Psychosocial Oncology**, 15 (3/4), pp.59-80.

Castle Peak Hospital. (1999) **Annual Report 1998-99.** Hong Kong, Castle Peak Hospital, Hospital Authoirty.

Caudle, P. (1993) Providing culturally sensitive health care to Hispanic clients. **Nurse Practitioner**, 18 (12) December, pp.40-51.

Census and Statistics Department. (2003) **Thematic household survey report, No. 10.** Hong Kong SAR, Census and Statistics Department Social Surveys Section.

Census & Statistics Department. (2004) **Bi-annual census and statistics report, 2002-03**. Hong Kong SAR, China, HKSAR Government.

Champion, L.A. (1990) The relationship between social vulnerability and the occurrence of severely threatening life events. **Psychological Medicine**, 20 (suppl 1) February, pp.157-161.

Champion, L.A. & Goodall, G.M. (1994) Social support and mental health: positive and negative aspects. In: Tantam, D. & Birchwood, M.J. eds. **Seminars in psychology and the social sciences.** London, Royal College of Psychiatrists: pp.238-259.

Chan, S. & Yu, I.W. (2004) Quality of life of clients with schizophrenia. **Journal of Advanced Nursing**, 45, pp.72-83.

Chang, A.M. (1999) **Psychosocial nursing intervention to promote self-esteem and functional independence following stroke**. Ph.D. Thesis, Hong Kong, Department of Nursing, The Chinese University of Hong Kong.

Chen, S.W.H. & Davenport, D.S. (2005) Cognitive-behavioural therapy with Chinese American clients: cautions and modifications. **Psychotherapy: Theory, Research, Practice, Training**, 42 (1) Spring, pp.101-110.

Cherryholmes, C.C. (1992) Notes on pragmatism and scientific realism. **Educational Researcher**, 21, pp.13-17.

Chien, W.T., Chan, S., Morrissey, J. & Thompson, D. (2005) Effectiveness of a mutual support group for families of patients with schizophrenia. **Journal of Advanced Nursing,** 51 (6), pp.595-608.

Chien, W.T. & Chan, C.W.S. (2004) One-year follow-up of a multiple-family-group intervention for Chinese families of patients with schizophrenia. **Psychiatric Services**, 55 (11) November, pp.1276-1284.

Chien, W.T. & Norman, I. (2003) Educational needs of families caring for Chinese patients with schizophrenia. **Journal of Advanced Nursing**, 44 (5) December, pp.490-498.

Chien, W.T., & Norman, I. (2004). The validity and reliability of a Chinese version of the Family Burden Interview Schedule. **Nursing Research**, 53 (5) September-October, 314-322.

Chien, W.T., Norman, I. & Thompson, D.R. (2004) A randomized controlled trial of a mutual support group for family caregivers of patients with schizophrenia. **International Journal of Nursing Studies**, 41(6), pp.637-649.

Citron, M., Solomon, P. & Draine, J. (1999) Self-help groups for families of persons with mental illness: perceived benefits of helpfulness. **Community Mental Health Journal**, 35 (1) February, pp.15-30.

Chou, K.R. (2000) Caregiver burden: a concept analysis. **Journal of Pediatric Nursing,** 15 (6), pp.398-407.

Chou, K.R., LaMontagne, L.L. & Hepworth, J.T. (1999) Burden experienced by caregivers of relatives with dementia in Taiwan. **Nursing Research,** 48 (4) July/August, pp.206-214.

Chou, K.R., Liu, S.Y. & Chu, H. (2002) The effects of support groups on caregivers of patients with schizophrenia. **International Journal of Nursing Studies**, 39 (7) September, pp.713-722.

Clark, A. (1998) The qualitative-quantitative debate: moving from positivism and confrontation to post-positivism and reconciliation. **Journal of Advanced Nursing**, 27 (6), pp.1242-1249.

Clausen, J.A. & Yarrow, M.R. eds. (1955) The impact of mental illness on the family. **Journal of Social Issues**, 11, pp.3-64.

Clifford, P., Leiper, R., Lavender, A. & Pilling, S. (1991) **Assuring quality in mental health services: the QUARTZ system**. London, Research and Development for Psychiatry and Free Association Books.

Cohen, J. (1992) A power primer. **Psychological Bulletin**, 112 (1) January, pp.155-159.

Cohen, S. (1988) Psychological models of social support in the etiology of physical disease. **Health Psychology**, 7, pp.269-297.

Cohen, S. (2004) **Social relationships and health**. American Psychologist, 59 (8) November, 676-684.

Cohen, S., Gottlieb, B. & Underwood, L. (2000) Social relationships and health. In: Cohen, S., Underwood, L. & Gottlieb, B. eds. **Measuring and intervening in social support**. New York, Oxford University press. pp.3-25.

Cohen, S., Kessler, R.C. & Gordon, L.U. (1995) Strategies for measuring stress in psychiatric and physical disorders. In: Cohen, S., Kessler, R.C. & Gordon, L.U., eds. **Measuring stress**. New York, Oxford University Press. pp.3-28.

Cohen, S. & Wills, T.A. (1985) Stress, social support and the buffering hypothesis. **Psychological Bulletin,** 98 (2) September, pp.310-357.

Colahan, M. & Robinson, P.H. (2002) Multi-family groups in the treatment of young adults with eating disorders. **Journal of Family Therapy**, 24, 17-30.

Cole, R.E. & Reiss, D. eds. (1993) **How Do Families Cope with Chronic Illness?** Hillsdale, NJ, Lawrence Erlbaum Associates, Inc.

Cook, J.A., Heller, T. & Pickett-Schenk, S.A. (1999) The effects of support group participation on caregiver burden among parents of adult offspring with severe mental illness. **Family Relations**, 48 (4) October, pp.405-410.

Cook, J.A., Lefley, H.P., Pickett, S.A. & Cohler, B.J. (1994) Age and family burden among parents of offspring with severe mental illness. **American Journal of Orthopsychiatry**, 64, pp.435-447.

Cook, J.A. & Wright, E.R. (1995) Medical sociology and the study of severe mental illness: reflections on past accomplishments and directions for future research. **Journal of Health and Social Behaviour**, 36 (Extra issue), pp.95-114.

Coriell, M. & Choen, S. (1995) Concordance in the face of a stressful event: when do members of a dyad agree that one person supported the other? **Journal of Personality and Social Psychology**, 69, pp.289-299.

Corrigan, P.W. & McCracken, S.G. (1995) Psychiatric rehabilitation and staff development: educational and organisational models. **Clinical Psychology Review**, 15 (8), pp.699-719.

Cragan, J.F. & Wright, D.W. (1999) **Communicating in small groups: theory, process and skills.** 5th ed. Belmont, CA, Wadsworth Publications.

Craig, T.K.J., Garety, P., Power, P., Rahaman, N., Colbert, S., Fornells-Ambrojo, M. & Dunn, G. (2004) The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis. **British Medical Journal**, 329 (7474) November, pp.1067-1071.

Cuijpers, P. (1999) The effects of family interventions on relatives' burden: a meta-analysis. **Journal of Mental Health,** 8 (3), pp.275-285.

Cullum, N. (1994) Critical reviews of the literature. In: Hardey, M. & Mulhall, A. eds. **Nursing Research: theory and practice**. London: Chapman & Hall. pp.58-83.

Cunningham, A.J., Edmonds, C.V.I., Jenkins, G.P., Pollack, H., Lockwood, G.A. & Warr, D. (1998) A randomised controlled trial of the effects of group psychological therapy on survival in women with meta-static breast cancer. **Psycho-oncology**, 7, pp.508-517.

Davidson, K.P., Pennebaker, J.W. & Dickerson, S.S. (2000) Who talks? The social psychology of illness support groups. **American Psychologist**, 55 (2) February, pp.205-217.

De Giacomo, P., Pierri, G., Santoni, R.A., Buonsante, M., Vadruccio, F. & Zavoianni, L. (1997) Schizophrenia: a study comparing a family therapy following a paradoxical model plus psychotropic drugs and a group treated by the conventional clinical approach. **Acta Psychiatrica Scandinavica,** 95 (3), pp.183-188.

Dehar, M.A., Casswell, S. & Duignan, P. (1993) Formative and process evaluation of health promotion and disease prevention programs. **Evaluation Review**, 17 (1) February, pp.4-5.

Department of Health, UK (1999) **National Service Framework for Mental health: Modern Standards & Services Models.** London: NHS, Department of Health.

Department of Health, UK (2001) **The expert patient: a new approach to chronic disease management for the twenty-first century.** London: Department of Health. Retrieved 20 May 2005, from http://www.ohn.gov.uk /ohn/people/expert.

Dickerson, F.B. (2000) Cognitive-behavioural psychotherapy for schizophrenia: a review of recent empirical studies. **Schizophrenia Research**, 43(2/3) June, pp.71–90.

Dilk, M.N. & Bond, G.R. (1996) Meta-analytic evaluation of skills training research for individuals with severe mental illness. **Journal of Consulting and Clinical Psychology**, 64(6) December, pp.1337-1346.

Dixon, L., Adams, C. & Luckstead, A. (2000) Update on family psycho-education for schizophrenia. **Schizophrenia Bulletin**, 26 (1), pp.5-20.

Dixon, L., Lyles, A., Scott, J., Postrado, L., Goldman, H. & McGlynn, E. (1999) Services to families of adults with schizophrenia: from treatment recommendations to dissemination. **Psychiatric Services,** 50 (2) February, pp.233-238.

Dixon, L., McFarlane, W.R., Lefley, H., Lucksted, A., Cohen, M., Falloon, I., Mueser, K., Miklowitz, D., Solomon, P. & Sondheimer, D. (2001) Evidence-based practices for services to families of people with psychiatric disabilities. **Psychiatric Services**, 52 (7) July, pp.903–910.

Doyle, M., Carr, A., Rowen, S., Galvin, P., Lyons, S. & Cooney, G. (2003) Family-oriented treatment for people with alcohol problems in Ireland: a comparison of the effectiveness of residential and community-based programmes. **Journal of Family Therapy**, 25, pp.15-40.

Drake, R.J., Haley, C.J., Akhar, S. & Lewis, S. (2000) Causes and consequences of duration of untreated psychosis in schizophrenia. **British Journal of Psychiatry,** 177 (6) December, pp.511-515.

Drury, V., Birchwood, M., Cochrane, R. & Macmillan, F. (1996) Cognitive therapy and recovery from acute psychosis: a controlled trial I. Impact on psychotic symptoms. **British Journal of Psychiatry,** 169 (5) November, pp.593-601.

Dunkin, J.J. & Hanley, C.A. (1998) Dementia caregiver burden: a review of the literature and guidelines for assessment and intervention. **American Academy of Neurology**, 51 (Suppl 1), S53-S60.

Durkheim, E. (1951) **Suicide**. New York, Free Press (Original work published in 1897).

Dyck, D.G., Hendryx, M.S., Short, R.A., Voss, W.D. & McFarlane, W.R. (2002) Service use among patients with schizophrenia in psychoeducational multiple-family group treatment. **Psychiatric Services**, 53 (6) June, pp.749-754.

Dyck, D.G., Short, R.A., Hendryx, M.S., Norell, D., Myers, M., Patterson, T., McDonell, M.G., Voss, W.D. & McFarlane, W.R. (2000) Management of negative symptoms among patients with schizophrenia attending multiple-family groups. **Psychiatric Services**, 51 April, pp.513-519.

Ensel, W.M. & Lin, N. (1991) The life stress paradigm and psychological distress. **Journal of Health and Social Behavior**, 32, pp.321-341.

Epstein, N.B., Baldwin, L.M. & Bishop, D.S. (1983) The McMaster family assessment device. **Journal of Marital and Family Therapy**, 9 (2) April, pp.171-180.

Eva, F.J. & Puri, B.K. (1995) Expressed emotion and a hypothetical model of relapse in schizophrenia. **Medical Hypotheses**, 45, pp.99-105.

Fadden, G. (1997) Implementation of family interventions in routine clinical practice following staff training programmes: a major cause for concern. **Journal of Mental Health**, 6, pp.599-612.

Fadden, G. (1998) Research update: psychoeducational family interventions. **Journal of Family Therapy**, 20, pp.293-309.

Falloon, I.R.H., Boyd, J.L. & McGill, C.W. (1984) **Family care of schizophrenia**. New York: Guilford Press.

Falloon, I.R.H., Boyd, J.L., McGill, C.W., Razani, J., Moss, H.B. & Gilderman, A.M. (1982) Family management in the prevention of exacerbations of schizophrenia: a controlled study. **New England Journal of Medicine,** 306 (4) June, pp.1437-1440.

Falloon, I.R.H., Boyd, J.L., McGill, C.W., Williamson, M., Razani, J., Moss, H.B., Gilderman, A.M. & Simpson, G.M. (1985) Family management in the prevention of morbidity in schizophrenia. Clinical outcome of a two-year longitudinal study. **Archives of General Psychiatry,** 42 (9) December, pp.887-896.

Falloon, I.R.H. & Pederson, J. (1985) Family management in the prevention of morbidity of schizophrenia: the adjustment of the family unit. **British Journal of Psychiatry,** 147 (2) August, pp.156-163.

Fenton, W.S. (2000) Evolving perspectives on individual psychotherapy for schizophrenia. **Schizophrenia Bulletin,** 26 (1), pp.47-72.

Festinger, L.A. (1954) A theory of social comparison processes. **Human Relations**, 7 (2) February, pp.117-140.

Fink, A. (1995) **How to design surveys**. Thousands Oaks, CA, Sage.

Fisher, G.A. & Tessler, R.C. (1986) Family bonding of the mentally ill: an analysis of family visits with residents of board and care homes. **Journal of Health and Social Behaviour**, 27, pp.236-249.

Fitzpatrick, R. & Boulton, M. (1994) Qualitative methods for assessing health care. **Quality in Health Care**, 3 (2) June, pp.107-113.

Fung, C. & Ma, A. (1997) Family management in schizophrenia. **Hong Kong Journal of Mental Health,** 26 (2) December, pp.53-63.

Fung, W.Y. & Chien W.T. (2002) The effectiveness of a mutual support group for family caregivers of a relative with dementia. **Archives of Psychiatric Nursing**, XVI (3), pp.134-144.

Galinsky, M.J. & Schopler, J.H. eds. (1995). **Support groups: current perspectives on theory and practice.** New York, Harworth Press.

Gazda, G.M., Ginter, E.J. & Horne, A.M. (2001) **Group counselling and group psychotherapy: theory and application.** Boston, Allyn and Bacon. pp.33-94.

Gibaldi, M. & Sullivan, S. (1997) Intention-to-treat analysis in randomised trials: who gets counted? **Journal of Clinical Pharmacology,** 37 (8) August, pp.667-672.

Gidron, B. & Chesler, M. (1995) Universal and particular attributes of self-help: a framework for international and intra-national analysis. In: Lavoie, F., Borkman, T. & Gidron, B. eds. **Self-help and mutual aid groups: international and multicultural perspectives**. New York, Haworth. pp.1-44.

Gidron, B., Guterman, N.B. & Hartman, H. (1990) Stress and coping patterns of participants and non-participants in self-help groups for parents of the mentally ill. **Community Mental Health Journal,** 26 (6) December, pp.483-496.

Gillman, M.W. & Runyan, D.K. (1984) Bias in treatment assignment in controlled clinical trials. **New England Journal of Medicine**, 310 (24) June, 1610-1612.

Gleeson-Kreig, J., Bernal, H. & Woolley, S. (2002) Role of social support in the self-management of diabetes mellitus among a Hispanic population. **Public Health Nursing**, 19 (3) May/June, pp.215-222.

Glenn, E. & Drew, F. (1992) **Rules of thumb for social learning**. Cambridge, Massachusetts Institute of Technology.

Glick, I., Spencer, J., Clarkin, J., Haas, G., Lewis, A., Peyser, J., DeMane, N., Good-Ellis, M., Harris, E. & Lestelle, V. (1990) A randomized trial of family intervention IV: follow-up results for subjects with schizophrenia. **Schizophrenia Research,** 3 (3) May/June, pp.187-200.

Goldstein, M.J. & Miklowitz, D.J. (1994) Family intervention for persons with bipolar disorder. **New Directions for Mental Health Services,** (62) Summer, pp.23-35.

Goldstein, M., Rodnick, E., Evans, J., May, P. & Steinberg, M. (1978) Drug and family therapy in the aftercare of acute schizophrenics. **Archives of General Psychiatry,** 35 (10) October, pp.1169-1177.

Gottlieb, B.H. (1988) **Marshalling social support: format, process, and effects**. Newbury Park, Sage Publications.

Gottlieb, B.H. (1992) Quandries in translating support concepts to intervention. In: Veiel, H.O.F. & Baumann, U. eds. **The meaning and measurement: the series in clinical and community psychology**. New York, Hemisphere. pp.293-309.

Gravetter, F.J. & Wallnau, L.B. (2000) **Statistics for the behavioural sciences**. 5th ed. Belmont, CA, Wadsworth.

Greenberg, J.S., Greenley, J.R. & Benedict, P. (1994) Contributions of persons with serious mental illness to their families. **Hospital and Community Psychiatry**, 45, pp.475-480.

Greenberg, L.S. (2002) **Emotion-focused therapy: coaching clients to work through their feelings.** Washington, DC, American Psychiatric Association.

Griffiths, P. (1999) The Challenges of implementing evidence-based healthcare. **British Journal of Community Nursing**, 4 (3) March, pp.142-147.

Grol, R. (1997) Personal paper: beliefs and evidence in changing clinical practice. **British Medical Journal**, 315 (7105) August, pp.418-421.

Guba, E. & Lincoln, Y. (1989) **Fourth generation evaluation**. London, Sage Publications.

Gurman, A.S. & Kniskern, D.P. eds. (1991) **Handbook of Family Therapy, Volume II.** New York, Brunner/Mazel.

Guyatt, G., Jaeschke, R., Heddle, N., Cook, D., Shannon, H. & Walter, S. (1995). Basic statistics for clinicians: 2. Interpreting study results: confidence intervals. **Canadian Medical Association Journal**, 152 (2) January, pp.169-173.

Haddock, G., Tarrier, N., Spaulding, W., Yusupoff, L., Kinney, C. & McCarthy, E. (1998) Individual cognitive-behavioural therapy in the treatment of hallucinations and delusions: a review. **Clinical Psychology Review,** 18 (7), pp.821-838.

Haddock, G., Tarrier, N., Morrison, A.P., Hopkins, R., Dake, R. & Lewis, S. (1999) A pilot study evaluating the effectiveness of individual in-patient cognitive behavioural therapy in early psychosis. **Social Psychiatry and Psychiatric Epidemiology,** 34 (5), pp.254-258.

Hammond, T.V. & Deans, C. (1995) A phenomenological study of families and psychoeducation support groups. **Journal of Psychosocial Nursing & Mental Health Services,** 33(10) October, pp.7-12.

Hanson, W.E., Creswell, J.W., Clark, V.L.P., Petska, K.S., Creswell, J.D. (2005) Mixed methods research designs in counselling psychology mixed methods research designs in counselling

psychology (Special Issue - Knowledge in Context: Qualitative Methods in Counselling Psychology Research). **Journal of Counseling Psychology**, 52 (2) April, pp.224-235.

Hatfield, A.B. ed. (1994) **Family interventions in mental illness**. New Directions for Mental Health Services, No. 62. San Francisco, CA: Jossey-Bass Inc.

Hatfield, A.B. & Lefley, H.P. (1987) **Families of the mentally ill: coping and adaptation.** New York, Guilford Press.

Hazel, N.A., McDonell, M.G., Short, R.A., Berry, C.M., Voss, W.D., Rodgers, M.L. & Dyck, D.G. (2004) Impact of multiple-family groups for outpatients with schizophrenia on caregivers' distress and resources. **Psychiatric Services**, 55 January, pp.35-41.

Helgeson, V.S. & Gottlieb, B.H. (2000) Support groups. In: Cohen, S. & Underwood, L.G. eds. **Social support measurement and intervention: a guide for health and social scientists**. London, Oxford University Press. pp.221-245.

Heller, T. & Factor, A. (1991) Permanency planning for adults with mental retardation living with family caregivers. **American Journal on Mental Retardation**, 96 (2), pp.163-176.

Heller, T., Roccoforte, J.A. & Cook, J.A. (1997a) Predictors of support group participation among families of persons with mental illness. **Family Relations**, 46 (4), pp.437-442.

Heller, T., Roccoforte, J.A., Hsieh, K., Cook, J.A. & Pickett, S.A. (1997b) Benefits of support groups for families of adults with severe mental illness. **American Journal of Orthopsychiatry,** 67 (2) April, pp.187-198.

Herdelin, A.C. & Scott, D.L. (1999) Experimental studies of the program of Assertive Community Treatment (PACT): a meta-analysis. **Journal of Disability and Policy Studies**, 10, 53-89.

Herz, M.I., Glazer, W. & Mostert, M. (1991) Intermittent vs maintenance medication in schizophrenia. **Archives of General Psychiatry**, *48*, pp.333-339.

Hintz, J.L. (1996) **PASS user's guide: PASS 6.0 - power analysis and sample size for Windows**. Kaysville, Utah: NCSS.

Hirsch, S. & Leff, J. (1975) **Abnormalities in parents of schizophrenics**. Maudsley Monograph No. 22. London: Oxford University Press.

Hoenig, J. & Hamilton, M. (1969) The schizophrenic patient in the community and his effect on the household. **International Journal of Social Psychiatry**, 12, pp.165-176.

Hogarty, G.E., Anderson, C.M., Reiss, D.J., Kornblith, S.J., Greenwald, D.P., Ulrich, R.F. & Carter, M. (1991) Family psychoeducation, social skills training, and maintenance chemotherapy in the aftercare treatment of schizophrenia, II: two-year effects of a controlled study on relapse and adjustment. **Archives of General Psychiatry,** 48 (5), pp.340-347.

Hogarty, G.E., Kornblith, S.J., Greenwald, D., DiBarry, A.L., Cooley, S., Ulrich, R.F., Carter, M. & Flesher, S. (1997) Three-year trials of personal therapy among schizophrenic patients living with or independent of family I. Description of study and effects on relapse rates. **American Journal of Psychiatry,** 154 (11) November, pp.1504-1513.

Horwitz, A.V. & Reinhard, S. (1992) Family management of labelled mental illness in a deinstitutionalised era: an exploratory study. In: Holstein, J.A. & Miller, G. eds. **Perspectives on social problems**. Greenwich, CT, JAI Press. pp.111-127.

Hospital Authority, Hong Kong. (2002) **Annual Report 2001-02**. Hong Kong SAR, China, Hospital Authority.

Hospital Authority, Hong Kong. (2003) **Annual Report 2002-03**. Hong Kong SAR, China, Hospital Authority.

Hsu, J. (1995) Family therapy for the Chinese: problems and strategies. In: Lin, T.Y., Tseng, W.S. & Yeh, E.K. eds. **Chinese societies and mental health.** Hong Kong, Oxford University Press. pp.295-307.

Humphreys, K. (1997) Individual and social benefits of mutual and self-help groups. **Social Policy**, 27 (3) Spring, pp.12-19.

Hurst, K. (1993) **Problem-solving in nursing practice.** London, Scutari Press.

Iodice, J.D. & Wodarski, J.S. (1987) Aftercare treatment for schizophrenics living at home. **Social Work,** 32 (2), pp.122-128.

Ivanović, M., Vuletić, Z. & Bebbington, P. (1994) Expressed emotion in the families of patients with schizophrenia and its influence on the course of illness. **Social Psychiatry and Psychiatric Epidemiology**, 29, pp.61-65.

Jablensky, A., Sartorius, N., Ernberg, G., Anker, M., Korten, A., Cooper, J.E., Day, R. & Bertelsen, A. (1992) Schizophrenia: manifestations, incidence and course in different cultures. A World Health Organisation ten-country study. **Psychological Medicine Monograph,** Suppl. 20.

Jacob, T. ed. (1987) **Family interaction and psychopathology.** New York, Plenum Press.

Jacobs, M.K. & Goodman, G. (1989) Psychology and self-help groups. **American Psychologist,** 44 (3) March, pp.536-545.

Jacobson, N.S., Roberts, L.J., Berns, S.B. & McGlinchey, J.B. (1999) Methods for defining and determining the clinical significance of treatment effects: description, application, and alternatives. **Journal of Consulting and Clinical Psychology,** 67 (3) June, pp.300-307.

Jacobson, N.S. & Truax, P. (1991) Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. **Journal of Consulting and Clinical Psychology,** 59 (1) February, pp.12-19.

Kane, J.M. & Marder, S.R. (1993) Psychopharmacologic treatment of schizophrenia. **Schizophrenia Bulletin,** 19 (2), pp.287-302.

Kane, J.M. & McGlashan, T.H. (1995) Treatment of schizophrenia. **Lancet**, 346, pp.820-825.

Kapur, S. & Remington, G. (2001) Atypical antipsychotics: new directions and new challenges in the treatment of schizophrenia. **Annual Review of Medicine**, 52 (1), pp.503-517.

Karanci, A.N. & Inandilar, H. (2002) Predictors of components of expressed emotion in major caregvieres of Turkish patients with schizophrenia. **Social Psychiatry and Psychiatric Epidemiology**, 37, pp.80-88.

Katz, L.F. (1997) **Self-help and support groups: a handbook for practitioners**. Thousand Oaks, CA, Sage Publications.

Katz, A.H. & Bender, E.I. eds. (1990) **Helping one another: self-help groups in a changing world.** Oakland, CA, Third party Publishing Company.

Kavanagh, D.J. (1992) Recent developments in expressed emotion and schizophrenia. **British Journal of Psychiatry**, 160, 601-620.

Kavanagh, D.J., Piatkowska, O., Clarke, D., O'Halloran, P., Manicavasagar, V., Rosen, A. & Tennant, C. (1993) Application of cognitive-behavioural family intervention for schizophrenia in multi-disciplinary teams: What can the matter be? **Australian Psychologist,** 28, pp.181-188.

Kavanagh, S., Opit, L., Knapp, M. & Beecham, J. (1995) Schizophrenia: shifting the balance of care. **Social Psychiatry and Psychiatric Epidemiology,** 30 (5), pp.206-212.

Kawachi, I. & Berkman, L.F. (2001) Social ties and mental health. **Journal of Urban Health: Bulletin of the New York Academy of Medicine**, 78, pp.458-467.

Kay, S.R., Fizzbein, A. & Opler, L.A. (1987) The Positive and Negative Syndrome Scale for schizophrenia. **Schizophrenia Bulletin**, 13, 261-276.

Keitner, G., Ryan, C., Miller, I., Epstein, N., Bishop, D. & Norman, W. (1990) Family functioning, social adjustment and recurrence of suicidality. **Psychiatry**, 53 (1) February, pp.17-30.

Kernis, M. (1995) **Efficacy, agency, and self-esteem**. New York, Plenum.

Kessler, R.C., Mickelson, K.D. & Zhao, S. (1997) Patterns and correlates of self-help group membership in the United States. **Social Policy**, 27 (3) Spring, pp.27-46.

Kimberly, K.C. (1997) **Group processes and structures: a theoretical integration.** Lanham, University Press of America.

Kingdon, D.G. & Turkington, D. (1994) **Cognitive-behavioural therapy of schizophrenia**. New York, Guiford Press.

Koettgen, C., Soennichsen, I., Mollenhauer, K. & Jurth, R. (1984) Group therapy with the families of schizophrenic patients: results of the Hamburg Camberwell Family Interview study III. **International Journal of Family Psychiatry,** 5 (1), pp.83-94.

Kouzis, A.C., Ford, D.E. & Eaton, W.W. (2000) Social relationships and psychiatric help-seeking. **Research in Community and Mental Health**, 11, pp.65-84.

Krezman, J. (1985). Averageness. **The Recovery Reporter**, 48 (5), pp.1-2.

Kuipers, L. & Bebbington, P. (1985) Relatives as a resource in the treatment of functional illness. **British Journal of Psychiatry,** 147 November, pp.465-470.

Kurtz, E. (1981) **Shame and guilt: characteristics of the dependency cycle**. Center City, MN, Hazelden.

Kurtz, L.F. (1997) **Self-help and support groups: a handbook for practitioners**. Thousand Oaks, CA, Sage Publications.

Kurtz, L.F. & Powell, T.J. (1987) Three approaches to understanding self-help groups. **Social Work with Groups**, 10 (3) Fall, pp.69-80.

Kyrouz, E.M., Humphreys, K. & Loomis, C. (2002) A review of research on the effectiveness of self-help mutual aid groups. In: White, B.J. & Madara, E.J. eds. **The American Self-help Clearinghouse self-help group sourcebook.** 7th ed. Cedar Knolls, NJ, American Self-help Clearinghouse.

Lafuze, A.J.E., Barrickman, P.J., Van Dusen, C. & Fompa-Loy, J. (1997) Educational needs of families of mentally ill adults. **Psychiatric Services**, 48 (8) August, 1072-1074.

Lakey, B. & Cohen, S. (2000) Support theory and measurement. In: Cohen, S., Underwood, L. & Gottlieb, B. eds. **Measuring and intervening in social support**. New York, Oxford University press. pp.29-52.

Lam, D.H. (1991) Psychosocial family intervention in schizophrenia: a review of empirical studies. **Psychological Medicine,** 21, pp.423-441.

Langford, C.P.H., Bowsher, J., Maloney, J.P. & Lillis, P.P. (1997) Social support: a conceptual analysis. **Journal of Advanced Nursing**, 25 (1) January, pp.95-100.

Lazarus, R.S. & Folkman, S. (1984) **Stress and coping**. New York, Springer.

Lee, K.L. (1999) **Study on the effect of the pre-discharge rehabilitation program on the level of functioning of chronic schizophrenic patients in Hong Kong**. Master Thesis, Hong Kong, Department of Nursing, The Chinese University of Hong Kong.

Lee, R.M. & Liu, T.H.T. (2001) Coping with intergenerational family conflict: comparison of Asian American, Hispanic, and European American college students. **Journal of Counseling Psychology**, 48 (4) October, pp.410-419.

Leff, J. (1994) Working with the families of schizophrenic patients. **British Journal of Psychiatry,** 164 (1) January, pp.71-76.

Leff, J., Berkowitz, R., Shavit, N., Strachen, A., Glass, I. & Vaughn, C. (1989) A trial of family therapy vs a relative group for schizophrenia. **British Journal of Psychiatry,** 154 (1) January, pp.58-66.

Leff, J., Berkowitz, R., Shavit, N., Strachen, A., Glass, I. & Vaughn, C. (1990) A trial of family therapy vs a relatives' group for schizophrenia: two-year follow-up. **British Journal of Psychiatry,** 157 (4) October, pp.571-577.

Leff, J., Kuipers, L., Berkowitz, R., Eberlein-Fries, R. & Sturgeon, D. (1982) A controlled trial of intervention in the families of schizophrenic patients. **British Journal of Psychiatry,** 141 (2) August, pp.121-134.

Leff, J., Kuipers, L., Berkowitz, R. & Sturgeon, D. (1985) A controlled trial of social intervention in the families of schizophrenic patients: two year follow-up. **British Journal of Psychiatry,** 146 (6) June, pp.594-600.

Lefley, H.P. (1996) **Family caregiving in mental illness.** Thousand Oaks, CA, Sage Publications.

Lehman, A.F. & Steinwachs, D.M. (1998) At issue - Translating research into practice: the Schizophrenia Patient Outcomes Research Team (PORT) treatment recommendations. **Schizophrenia Bulletin**, 24 (1) January, pp.1–9.

Lehman, A.F., Steinwachs, D.M. & the Survey Co-investigators of the PORT project (1998) Patterns of usual care for schizophrenia: initial results from the schizophrenia patient outcomes research team (PORT) client survey. **Schizophrenia Bulletin,** 24 (1) January, pp.11-20.

Lemmens, G.M., Wauters, S., Heireman, M., Eisler, I., Lietaer, G. & Sabbe, B. (2003) Beneficial factors in family discussion groups of a psychiatric day clinic: perceptions by the therapeutic team and the families of the therapeutic process. **Journal of Family Therapy**, 25, pp.41-63.

Leung, K.K., Chien, W.T. & Mackenzie, A.E. (2000) Needs of Chinese families of critically ill patients. **Western Journal of Nursing Research,** 22 (7) November, pp.826-840.

Leung, M., Wong, J. & Siu, V. (1993) The emergence of a self-help association for relatives of the mentally disturbed in Hong Kong. In: Social Sciences Research Centre. ed. **Psychiatric rehabilitation: the Asian experience.** Hong Kong, Department of Social Work and Social Administration, University of Hong Kong.

Levene, J.E., Newman, F. & Jeffries, J.J. (1989) Focal family therapy outcome study, I: patient and family functioning. **Canadian Journal of Psychiatry,** 34 (7) October, pp.641-647.

Levine, M. & Perkins, D. (1987) **Principles of community psychology: perspectives and applications**. New York, Oxford University Press.

Levy, P.S. (1991) **Sampling of populations: methods and applications**. New York, Wiley.

Lieberman, M.A. & Snowden, L.R. (1994) Problems in assessing prevalence and membership characteristics of self-help group participants. In: Powell, T.J. ed. **Understanding the self-help organization: framework and findings**. Thousand Oaks, CA, Sage Publications. pp.32-49.

Lin, T.Y., Tseng, W.S. & Yeh, E.K. eds. (1995) **Chinese societies and mental health.** Hong Kong, Oxford University Press.

Lorig, K., Holman, H., Sobel, D. & Laurent, D. (2000) Living a healthy life with chronic conditions: self-management of heart disease, arthritis, stroke, diabetes, asthma, bronchitis, emphysema and others, 2nd edn. Boulder, Bull Publishing.

Loukissa, D.A. (1995) Family burden in chronic mental illness: a review of research studies. **Journal of Advanced Nursing**, 21 (2) February, pp.248-255.

Luckstead, A. & Dixon, L. (1999) Quality of care in services to family members of people with serious mental illness. **Mental Health Services Research**, 1 (4), pp.223-230.

Luke, D.A., Roberts, L. & Rappaport, J. (1993) Individual, group context, and individual-group fit predictors of self-help group attendance. **Journal of Applied Behavioural Science,** 29 (2) June, pp.216-238.

Lukens, E., Thorning, H. & Herman, D. (1999) Family psychoeducation in schizophrenia: emerging themes and challenges. **Journal of Practice in Psychological and Behavioural Health**, November, 314-325.

Ma, J. (1992) Social support, mutual aid groups, the mentally ill and their families. **Hong Kong Journal of Mental Health,** 21 (1) June, pp.16-27.

Ma, K.Y. & Yip, K.S. (1997) The importance of an effective psychiatric community care service for chronic mental patients in Hong Kong. **Hong Kong Journal of Mental Health,** 26 (1) June, pp.28-35.

MacCarthy, B., Lesage, A., Brewin, C.R., Brugha, T.S., Mangen, S. & Wing, J.K. (1989) Needs for care among the relatives of long-term users of day care. A report from the Camberwell High Contact Survey. **Psychological Medicine,** 19 (3) August, pp.725-736.

Madianos, M.S., Gournas, G., Tomaras, V., Kapsali, A. & Stefanis, C. (1994) Family atmosphere on the course of chronic schizophrenia treated in a community mental health center; a prospective longitudinal study. In: Stefanis, C. & Rabavilas, A. eds. **Schizophrenia: recent biosocial developments.** New York, Human Sciences Press. pp.246-256.

Magliano, L., Marasco, C., Fiorillo, A., Malangone, C., Guarneri, M. & Maj, M. (2002) The impact of professional and social network support on the burden of families of patients with schizophrenia in Italy. **Acta Psychiatrica Scandinavica**, 106, pp.291-298.

Mak, K.Y., Wong, M.C., Ma, L.K. & Fung, S.C. (1997) A cost-effectiveness study of a community-based family management rehabilitation programme for schizophrenic outpatients in Hong Kong: a six-month report. **Hong Kong Journal of Psychiatry,** 7 (2) August, pp.26-35.

Malla, A.K. & Norman, R.M.G. (2002) Early intervention in schizophrenia and related disorders: advantages and pitfalls. **Current Opinion in Psychiatry,** 15 (1) January, pp.17-23.

Mankowski, E.S., Humphreys, K. & Moos, R.H. (2001) Individual and contextual predictors of involvement in Twelve-step self-help groups after substance abuse treatment. **American Journal of Community Psychology**, 29 (4) August, pp.537-563.

Mari, J.J. & Streiner, D. (1996) **Family intervention for people with schizophrenia**. In: The Cochrane Library, Issue 1, 1996. Oxford, Cochrane Library Update Software [Electronic database].

Marsh, D. (1992) **Families and mental illness: new directions in professional practice.** New York, Praeger.

Marsh, D.T. (1994) The psychodynamic model and services for families: issues and strategies. In: Lefley, H., Wasow, M. eds. **Helping families cope with mental illness.** Chur, Switzerland, Harwood Academic Publishers. pp.105-128.

Marsh, D.T. (1998) **Serious mental illness and the family: the practitioner's guide.** New York, John Wiley & Sons.

Marsh, D. & Johnson, D. (1997) The family experience of mental illness: implications for interventions. **Professional Psychological Research and Practice**, 28, pp.229-237.

Martens, L. & Addington, J. (2001) The psychological well being of family members of individuals with schizophrenia. **Social Psychiatry and Psychiatric Epidemiology**, 36, pp.128-133.

Mason, P., Harrison, G., Glazebrook, C., Croudace, T. & Medley, I. (1996) The course of schizophrenia over 13 years. A report from the International Study on Schizophrenia (IsoS) coordinated by the WHO. **British Journal of Psychiatry**, 169 (5) November, pp.580-586.

Maton, K.E. & & Salem, D.A. (1995). Organizational characteristics of empowering community settings: a multiple case study approach. **American Journal of Community Psychology**, 23 (5) October, pp.631-656.

Maton, K.I. (1993) Moving beyond the individual level of analysis in mutual help groups research: an ecological paradigm. **Journal of Applied Behavioural Science**, 29 (2) June, pp.272-286.

Matthews, J.N.S. (2000) **An introduction to randomized controlled clinical trials**. London, Arnold.

Maurin, J.T. & Boyd, C.B. (1990) Burden of mental illness on the family: a critical review. **Archives of Psychiatric Nursing**, *4* (2), pp.99-107.

McCallion, P. & Toseland, R.W. (1995) Supportive group interventions with caregivers of frail older adults. **Social Work with Groups**, 18 (1), pp.11-25.

McCubbin, M. & McCubbin, H. (1993) Families coping with illness: the resiliency model of family stress, adjustment and adaptation. In: Danielson, C., Hamel-Bissell, B., Winstead-Fry, P. eds. **Families, health and illness: perspectives on coping and intervention.** St. Louis, Mosby. pp.21-63.

McDonell, M.G., Short, R.A., Berry, C.M. & Dyck, D.G. (2004) Burden in schizophrenia caregivers: impact of family psychoeducation and awareness of patient suicidality. **Family Process**, 42 (1) Spring, pp.91-103.

McFarlane, W.R. (2002) **Multifamily groups in the treatment of severe psychiatric disorders**. New York, Guilford Press.

McFarlane, W.R., Dixon, L., Lukens, E. & Lucksted, A. (2003) Family **psychoeducation** and schizophrenia: a review of the literature. **Journal of Marital & Family Therapy**, 29 (2) April, pp.223-245.

McFarlane, W.R., Link, B., Dushay, R., Marchal, J. & Crilly, J. (1995a) Psychoeducational multiple family groups: four-year relapse outcome in schizophrenia. **Family Process**, 34 (2) June, pp.127-144.

McFarlane, W.R., Lukens, E., Link, B., Dushay, R., Deakins, S.A., Newmark, M., Dunne, E.J., Horen, B. & Toran, J. (1995b) Multiple-family groups and psychoeducation in the treatment of schizophrenia. **Archives of General Psychiatry,** 52 (8) August, pp.679-687.

McFarlane, W.R., Stastny, P. & Deakins, S. (1992) Family aided assertive community treatment: a comprehensive rehabilitation and intensive case management approach for persons with schizophrenic disorders. **New Directions in Mental Health Services**, 53, pp.43-54.

McGraw, K.O. & Wong, S.P. (1996) Forming inferences about some intraclass correlation coefficients. **Psychological Methods**, 1 (1) March, pp.36-40.

McGurk, S.R. (1999) The effects of clozapine on cognitive functioning in schizophrenia. **Journal of Clinical Psychiatry**, 60 (suppl 12), pp.24-29.

Medical Research Council. (1998) **MRC Guidelines for good clinical practice in clinical trials.** London, MRC.

Medvene, L. & Krauss, D. (1989) Causal attributions about psychiatric disability in a self-help group for families of the mentally ill. **Journal of Applied Social Psychology,** 19 (17, Pt.1), pp.1413-1430.

Meissen, G.J. & Volk, F. (1995) Predictors of burnout among self-help leaders. In: Lavoie, F., Borkman, T. & Gidron, B. eds. **Self-help and mutual aid groups: international and multicultural perspectives**. New York, Haworth. pp.241-262.

Meredith, W.H., Abbott, D.A., Tsai, R., Zheng, F.M. & Meredith, W.H. (1994) Healthy family functioning in Chinese cultures: an exploratory study using the Circumplex Model. **International Journal of the Sociology of the Family,** 24 (1) Spring, pp.147-157.

Miklowitz, D.J. (1994) Family risk indicators in schizophrenia. **Schizophrenia Bulletin,** 20 (1), pp.137-150.

Milburn, K., Fraser, E., Secker, J. & Pavis, S. (1995) Combining methods in health promotion research: some considerations about appropriate use. **Health Education Journal**, 54 (3) September, pp.347-356.

Miles, M.B. & Huberman, A.M. (1994) An expanded sourcebook: qualitative data analysis. 2nd ed. Thousand Oaks, CA, Sage Publications.

Miller, I., Epstein, N.B., Bishop, D.A. & Keitner, G. (1985) The McMaster Family Assessment Device: reliability and validity. **Journal of Marital and Family Therapy**, 11 (3) July, pp.345-356.

Mingyuan, Z., Hegin, Y., Chengde, Y., et al. (1993) Effectiveness of psychoeducation of relatives of schizophrenic patients: a prospective cohort study in five cities of China. **International Journal of Mental Health**, 22, pp.47-59.

Mittelman, M. (2005) Taking care of the caregivers. **Current Opinion in Psychiatry**, 18 (6) November, pp.633-639.

Montero, I., Asencio, A., Hernandez, I., Masanet, M.J., Lacruz, M., Bellver, F., Iborra, M. & Ruiz, I. (2001) Two strategies for family intervention in schizophrenia: a randomised trial in a Mediterranean environment. **Schizophrenia Bulletin**, 27 (6), pp.661-670.

Montori, V. & Guyatt, G.H. (2001) Intention-to-treat principle. **Canadian Medical Association Journal,** 165 (10) November, pp.1339-1341.

Moos, R.H., Finney, J. & Maude-Griffon, P. (1993) The social climate of the self-help and mutual support groups: assessing group implementation, process and outcome. In: McCrady, B.S. & Miller, W.R. eds. **Research on Alcoholics Anonymous: opportunities and alternatives**. New Brunswick, N.J., Rutgers Centre for Alcohol Studies. pp.251-270.

Morse, J.M. (1997) **Completing a qualitative project, details and dialogue**. London, Sage.

Morse, J.M. & Field, P.A. (1995) **Qualitative research methods for health professionals**. 2nd ed. Thousand Oaks, CA, Sage Publications.

Morse, J.M., Penrod, J. & Hcpcey, J. (2000) Qualitative outcome analysis: evaluating nursing interventions for complex clinical phenomena. **Image - Journal of Nursing Scholarship**, 32(2) Second Quarter, pp.125-130.

Morse, J.M. & Richards, L. (2002) **Read-me first for a user's guide to qualitative methods.** Thousand Oaks, CA, Sage Publications.

Mueser, K.T. (2003). **Mental Health Guidelines - Family services for severe mental illness**. February 2003. Illinois, USA, Behavioral Health Recovery Management, Fayette Companies & Chestnut Health Systems.

Mueser, K.T., Bond, G.R. & Drak, R.E. (2001) Community-based treatment of schizophrenia and other severe mental disorders: treatment outcomes. **Medscape General Medicine**, 3(1), 2001 [formerly published in Medscape Psychiatry & Mental Health eJournal, 6(1), 2001]. Retrieved on 22nd March 2002 at: http://www.medscape.com/viewarticle/430529.

Mueser, K.T., Curran, P. J. & McHugo, G.J. (1997) Factor structure of the Brief Psychiatric Rating Scale in Schizophrenia. **Psychological Assessment**, 9 (3), pp.196-204.

Mueser, K.T. & Gingerich, S. (1994) **Coping with schizophrenia: a guide for families.** Oakland, CA, New Harbinger Publications.

Mueser, K.T., Gingerich, S. & Rosenthal, C.K. (1994) Educational family therapy for schizophrenia: a new treatment model for clinical service and research. **Schizophrenia Research,** 13 (2) September, pp.99-108.

Mueser, K.T. & Glynn, S.M. (1999) **Behavioral family therapy for psychiatric disorders**, 2nd edn. Oakland, CA, New Harbinger Publications.

Mueser, K.T., Sengupta, A., Schooler, N.R., Bellack, A.S., Xie, H., Glick, I.D. & Keith, S.J. (2001) Family treatment and medication dosage reduction in schizophrenia: effects on patient social functioning, family attitudes, and burden. **Journal of Consulting and Clinical Psychology**, 69 (1) February, pp.3–12.

Munhall, P.L. (2001) **Nursing research: a qualitative perspective**, 3rd edn. Sudbury, Massachusetts, Jones & Bartlett Publishers.

National Collaborating Centre for Mental Health (2002) **Clinical Guideline 1 - Schizophrenia: core interventions in the treatment and management of schizophrenia in primary and secondary care.** December 2002. London, National Institute for Clinical Excellence.

National Health Service Centre for Reviews and Dissemination (2001) Undertaking systematic reviews of research on effectiveness: CRD's guidance for those carrying out or commissioning reviews (CRD Report Number 4, 2nd edn.). York, UK, University of York.

Ng, A., Philips, D. & Lee, W.K.M. (2002) Persistence and challenges to filial piety and informal support: a case study in Tuen Mun, Hong Kong. **Journal of Ageing Studies**, 16, pp.1-20.

Nichols, L. & Jenkinson, J. (1991) **Leading a support group**. New York, Chapman and Hall.

Noh, S. & Turner, R.J. (1987) Living with psychiatric patients: implications for the mental health and family members. **Social Science and Medicine**, 25 (3), pp.263-272.

Norton, S., Wandersman, A. & Goldman, C.R. (1993) Perceived costs and benefits of membership in a self-help group: comparison of members and non-members of the Alliance for the Mentally Ill. **Community Mental Health Journal,** 29 (2) April, pp.143-160.

Nowinski, J., Baker, S. and Carroll, K. (1995) **Twelve-step facilitation therapy manual: a clinical research guide for therapists treating individuals with alcohol abuse and dependence.** National Institutes of Health Publication 94-3722. Rockville, MD, National Institute on Alcohol Abuse and Alcoholism.

Nugter, A., Dingemans, P., Van Der Does, A.J.W., Linszen, D. & Gersons, B. (1997) Family treatment, expressed emotion and relapse in recent onset schizophrenia. **Psychiatry Research,** 72 (1) August, pp.23-31.

Ohaeri, J.U. (2003) The burden of caregiving in families with a mental illness: a review of 2002. **Current Opinion in Psychiatry**, 16 (4) July, pp.457-465.

Oldridge, M.L. & Hughes, I.C.T. (1992) Psychological well-being in families with a member suffering from schizophrenia: an investigation into longstanding problems. **British Journal of Psychiatry**, 161 (8) August, pp.249-251.

Overall, J.E. & Gorham, D.R. (1962) The Brief Psychiatric Rating Scale. **Psychiatric Reports**, 10, pp.799–812.

Pai, S. & Kapur, R.L. (1981) The burden on the family of a psychiatric patient: development of an interview schedule. **British Journal of Psychiatry**, 138 (1) April, pp.332-335.

Pai, S. & Kapur, R.L. (1982) Impact of treatment intervention on the relationship between dimensions of clinical psychopathology, social dysfunction and burden on the family. **Psychological Medicine,** 12 (3), pp.651-658.

Pakenham, K.I. & Dadds, M.R. (1987) Family care and schizophrenia: the effects of a supportive educational program on relatives' personal and social adjustment. **Australian and New Zealand Journal of Psychiatry**, 21 (4) December, pp.580-590.

Parahoo, K. (1997) **Nursing research: principles, process and issues.** Bsingstoke, Macmillan.

Parker, B.A. (1993) Living with mental illness: the family as caregivers. **Journal of Psychosocial Nursing**, 31 (3), pp.19-21.

Parry, G. (1995) Social support processes and cognitive therapy. In: Brugha, T.S. ed. **Social support and psychiatric disorder: research findings and guidelines for clinical practice.** Cambridge, University Press. pp.279-294.

Pawson, R. & Tilley, N. (1997) **Realistic evaluation.** London, Sage Publications.

Pearson, R.E. (1990) **Counselling and social support: perspectives and practice**. Newbury Park, CA, Sage Publications.

Pearson, V. & Ning, S.P. (1997) Family care in schizophrenia: an undervalued resource. In: Chan, C.L.W. & Rhind, N. eds. **Social work intervention in health care. The Hong Kong scene.** Hong Kong, Hong Kong University Press. pp.317-336.

Peirce, R.S., Frone, M.R., Russell, M. & Cooper, M.L. (1996) Financial stress, social support, and alcohol involvement: a longitudinal test of the buffering hypothesis in a general population survey. **Health Psychology**, 15, pp.38-47.

Penn, D.L., Mueser, K.T. (1996) Research update on the psychosocial treatment of schizophrenia. **American Journal of Psychiatry**, 153 (5) May, pp.607-617.

Penney, D. (1997) Friend or foe: the impact of managed care on self-help. **Social Policy**, 27 (4) Summer, pp.48-53.

Perkins, D.D. & Zimmerman, M.A. (1995) Empowerment theory, research, and application. **American Journal of Psychology**, 23 (5) October, pp.569-579.

Pharoah, F.M., Mari, J.J. & Streiner, D. (2001) **Family intervention for schizophrenia**. The Cochrane Library Reviews, Issue 3, 2001. Oxford, Cochrane Library Update Software [Electronic database].

Phelan, J., Link, B., Stueve, A. & Pescosolido, B. (2000) Public conceptions of mental illness in 1950 and in 1996: what is mental illness and is it to be feared? **Journal of Health and Social Behavior**, 41 June, pp.188-207.

Pickett, S.A. & Heller, T. (1998) Profession-led versus family-led support groups: exploring the differences. **Journal of Behavioral Health Services and Research**, 25 (4) November, 437-443.

Pierce, G.R., Sarason, B.R., Sarson, I.G., Joseph, H.J. & Henderson, C.A. (1996) Conceptualizing and assessing social support in the context of the family. In: Pierce, G.R., Sarason, B.R. & Sarason, I.G. eds. **Handbook of social support and the family**. New York, Plenum Press. pp.3-24.

Pai, S. & Kapur, R.L. (1981) The burden on the family of a psychiatric patient: development of an interview schedule. **British Journal of Psychiatry**, 138 (1) April, pp.332-335.

Pai, S. & Kapur, R.L. (1982) Impact of treatment intervention on the relationship between dimensions of clinical psychopathology, social dysfunction and burden on the family. **Psychological Medicine**, 12 (3) August, pp.651-658.

Parry, S.B. (1994) **From managing to empowering: an action guide to developing winning facilitation skills**. White Plains, New York, Quality Resources.

Pilling, S., Bebbington, P., Kuipers, E., Garety, P., Geddes, J., Orbach, G. & Morgan, C. (2002) Psychological treatments in schizophrenia, I: Meta-analysis of family intervention and cognitive behaviour therapy. **Psychological Medicine,** 32, pp.763-782.

Pitschel-Walz, G., Leucht, S., Bäuml, J., Kissling, W. & Engel, R.R. (2001) The effect of family interventions on relapse and re-hospitalisation in schizophrenia – A meta-analysis. **Schizophrenia Bulletin**, 27, pp.73-92.

Platt, S. (1985) Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales. **Psychological Medicine,** *15*, pp.383-393.

Polit, D. & Hungler, B.P. (1999) **Nursing research: principles and methods.** 6th ed. Philadelphia, Lippincott.

Pope, C., van Royen, P. & Baker, R. (2002) Qualitative methods in research on healthcare quality. **Quality & Safety in Health Care**, 11 (2) June, pp.148-152.

Portney, L.G. & Watkins, M.P. (2000) **Foundation of clinical research: application to practice**. 2nd ed. New Jersey, Prentice Hall.

Powell, T.J. (1993) Self-help research and policy issues. **Journal of Applied Behavioural Science**, 29 (2) June, pp.151-165.

Powell, T.J. ed. (1994) **Understanding the self-help organization: framework and findings**. Thousand Oaks, CA, Sage Publications.

Raj, L., Kulhara, P. & Avasthi, A. (1991) Social burden of positive and negative schizophrenia. **International Journal of Social Psychiatry**, *37*, pp.242-250.

Randolph, E.T., Eth, S., Glynn, S.M., Paz, G.G., Leong, G.B., Shaner, A.L., Strachan, A., Van Vort, W., Escobar, J.L. & Liberman, R.P. (1994) Behavioural family management in schizophrenia: outcome of a clinic-based intervention. **British Journal of Psychiatry,** 164 (4) April, pp.501-506.

Rappaport, J. (1993) Narrative studies, personal stories, and identity transformation in the mutual help context. **Journal of Applied Behavioural Science**, 29 (2) June, pp.239-256.

Reinhard, C.S. (1994) Living with mental illness: effects of professional support and personal control on caregiver burden. **Research in Nursing and Health,** 17, pp.79-88.

Reissman, F. (1997) Ten self-help principles. **Social Policy**, 27 (3) Spring, pp.6-11.

Reissman, F. & Carroll, D. (1995) **Redefining self-help: policy and practice**. San Francisco, Jossey-Bass.

Repper, J. & Brooker, C. (1998) Serious mental health problems in the community: the significance of policy, practice and research. In: Brooker, C. & Repper, J. eds. **Serious mental health problems in the community: policy, practice and research**. London, Bailliere-Tindall. pp.8-30.

Rhoades, H.M. & Overall, J.E. (1988) The semi-structured BPRS interview and rating scale. **Psychopharmacology Bulletin**, 24 (1), pp.101-104.

Robinson, D., Woerner, M.G., Pollack, S. & Lerner, G. (1996) Subject selection biases in clinical trials: data from a multicenter schizophrenia treatment study. **Journal of Clinical Psychopharmacology,** 16 (2) April, pp.170-176.

Roccoforte, J.A. (1991) **Stress, financial burden, and coping resources in families providing home care for adults with developmental disabilities.** Master of Psychology dissertation, Chicago, University of Illinois.

Rose, L., Mallinson, R.K. & Walton-Moss, B. (2002) A grounded theory of families responding to mental illness. **Western Journal of Nursing Studies**, 24, pp.16-36.

Rose, L.E., Mallinson, R.K. & Walton-Moss, B. (2004) Barriers to family care in psychiatric settings. **Journal of Nursing Scholarship**, 36 (1) March, pp.39-47.

Rossi, P.H. & Freeman, H.E. (1993) **Evaluation: a systematic approach.** 5th edition. Newbury Park, CA, Sage Publications.

Rothbaum, F., Rosen, K., Ujiie, T. & Uchida, N. (2002) Family system theory, attachment theory, and culture. **Family Process**, 41 (3) Fall, pp.328-350.

Rungreangkulkij, S. & Gilliss, C.L. (2000) Conceptual approaches to studying family caregiving for persons with severe mental illness. **Journal of Family Nursing**, 6(4), pp.341-366.

Sampson, P. & Murtha, R. (1997) **Group Process for the Health Professional.** 3rd ed. Albany, NY, DelMar Publishers.

Sandelowski, M. (2002) Re-embodying qualitative inquiry. **Qualitative Health Research**, 12 (1), pp.104-115.

Sarason, I.G., Levine, H.M., Basham, R.B. & Sarason, B. (1983) Assessing social support: the social support questionnaire. **Journal of Personality and Social Psychology**, 44 (1) January, pp.127-139.

Sarason, I.G., Sarason, B.R., Shearin, E.N. & Pierce, G.R. (1987) A brief measure of social support: practical and theoretical implications. **Journal of Social and Personal Relationships**, 4 (4) August, pp.497-510.

Saunders, J.C. (1999) Family functioning in families providing care for a family member with schizophrenia. **Issues in Mental Health Nursing,** 20 (2) March/April, pp.95-113.

Schene, A.H. (1990) Objective and subjective dimensions of family burden. Toward an integrative framework for research. **Social Psychiatry and Psychiatric Epidemiology**, 25, pp.289-297.

Schene, A.H., Tessler, R.C. & Gamanche, G.M. (1994) Instruments measuring family or caregiver burden in severe mental illness. **Social Psychiatry and Psychiatric Epidemiology**, 29, pp.228-240.

Schene, A.H., Tessler, R.C. & Gamache, G.M. (1996) Caregiving in severe mental illness; conceptualization and measurement. In: Knudsen, H.C. & Thronicroft, G. eds. **Mental health service evaluation.** Cambridge, UK, Cambridge University Press. pp.296-316.

Schiff, M. & Bargal, D. (2000) Helping characteristics of self-help and support groups: their contribution to participants' subjective well-being. **Small Group Research**, 31 (3), pp.275-304.

Schneider, L.C. & Struening, E.L. (1983) SLOF: A behavioural rating scale for assessing the mentally ill. **Social Work Research and Abstracts**, 19 (3), pp.9-21.

Schooler, N.R., Keith, S.J., Severe, J.B., Matthews, S.M., Bellack, A.S., Glick, I.D., Hargreaves, W.A., Kane, J.M., Ninan, P.T., Frances, A., Jacobs, M., Lieberman, J.A., Mance, R., Simpson, G.M. & Woerner, M.G. (1997) Relapse and re-hospitalization during the maintenance treatment of schizophrenia. The effects of dose reduction and family treatment. **Archives of General Psychiatry,** 54 (5) May, pp.453-463.

Schulz, K.F., Chalmers, I., Hayes, R.J. & Altman, D.G. (1995) Empirical evidence of bias: dimensions of methodological quality associated with estimates of treatment effects in controlled trials. **Journal of the American Medical Association**, 273 (5) February, pp.408-412.

Sellwood, W., Barrowclough, C., Tarrier, N., Quinn, J., Mainwaring, J. & Lewis, S. (2001) Needs-based cognitive-behavioural family intervention for carers of patients suffering from schizophrenia: 12-month follow-up. **Acta Psychiatrica Scandinavica**, 104 (5) November, pp.346-355.

Sensky, T., Turkington, D., Kingdon, D., Scott, J.L., Scott, J., Siddle, R., O'Carroll, M. & Barnes, T.R.E. (2000) A randomized controlled trial of cognitive-behavioural therapy for persistent symptoms of schizophrenia resistant to medication. **Archives of General Psychiatry,** 57 (2) February, pp.165-172.

Sibbald, B. & Roland, M. (1998) Understanding controlled trials: why are randomised controlled trials important? **British Medical Journal**, 316 (7126) January, pp.201.

Sidley, G.L., Smith, J. & Howells, K. (1991) Is it ever too late to learn? Information provision to relatives of long-term schizophrenia sufferers. **Behavioural Psychotherapy**, 19, pp.496-500.

Siegel, K., Raveis, V., Mor, V. & Houts, P. (1991) The relationship of spousal caregiver burden to patient disease and treatment-related conditions. **Behavioural Psychotherapy**, 19, pp.305-320.

Smith, A.R. (1991) **Alcoholics Anonymous: a social world perspective**. Ph.D. thesis, San Diego, University of California.

Solomon, P. (1996) Moving from psychoeducation to family education for families of adults with serious mental illness. **Psychiatric Services**, 47 (12) December, pp.1364-1370.

Solomon, P. (2000) Interventions for families of individuals with schizophrenia: maximising outcomes for their relatives. **Disease Management and Health Outcomes**, 8 (4) October, pp.211-221.

Solomon, P. & Draine, J. (1995) Subjective burden among family members of mentally ill adults: relation to stress, coping, and adaptation. **American Journal of Orthopsychiatry,** 65, pp.419-427.

Solomon, P., Draine, J., Mannion, E. & Meisel, M. (1996) The impact of individualised consultation and group workshop of family education interventions on ill relative outcomes. **Journal of Nervous and Mental Diseases**, 184 (4) April, pp.252-254.

Solomon, P., Draine, J., Mannion, E. & Meisel, M. (1997) Effectiveness of two models of brief family education: retention of gains by family members of adults with serious mental illness. **American Journal of Orthopsychiatry**, 67 (2) April, pp.177-186.

Speer, D.C. (1992) Clinically significant change: Jacobson and Truax (1991) revisited. **Journal of Consulting and Clinical Psychology,** 60 (3) June, pp.402-408.

Speer, D.C. (1998) **Mental health outcome evaluation**. San Diego, California, Academic Press.

Spencer, J.H., Glick, I.D., Haas, G.L., Clarkin, J.F., Lewis, A.B., Peyser, J., DeMane, N., Good-Ellis, M., Harris, E. & Lestelle, V. (1988) A randomized clinical trial of inpatient family intervention, III: effects at 6-month and 18-month follow-ups. **American Journal of Psychiatry,** 145 (9) September, pp.1115-1121.

Spiegel, D., Bloom, J.R,. Kraemer, H.C. & Gottheil, E. (1989) Effect of psychosocial treatment on survival of patients with metastatic breast cancer. **Lancet**, 2 (8668) October, pp.888-891.

Stein, C.H. & Wemmerus, V.A. (2001) Searching for a normal life: personal accounts of adults with schizophrenia, their parents and well-siblings. **American Journal of Community Psychology**, 29 (5) October, pp.725-746.

Stein, L.I. & Santos, A.B. (1998) **Assertive community treatment of persons with severe mental illness**. New York, Norton.

Steinberg, D.M. (1997) **The mutual-aid approach to working with groups: helping people help each other.** Northvale, NJ, Jason Aronson.

Steinglass, P. (1998) Multiple family discussion groups for patients with chronic medical illness. **Families, Systems and Health**, 16, pp.55-70.

Stevens, J.P. (2002) **Applied multivariate statistics for the social sciences**. 4th edition. Mahwah, New Jersey, Lawrence Erlbaum Associates, Inc.

Stewart, M.J. (1990) Expanding theoretical conceptualizations of self-help groups. **Social Science and Medicine**, 31 (9) September, pp.1057-1066.

Sun, Y.K.S. & Cheung, S.K. (1997) Family functioning, social support to families and symptom remittance of schizophrenia. **Hong Kong Journal of Psychiatry**, 7 (2), pp.19-25.

Swanson, A.J., Pantalon, M.V. & Cohen, K.R. (1999) Motivational interviewing and treatment adherence among psychiatric and dually diagnosed patients. **Journal of Nervous and Mental Disorders**, 187, pp.630-635.

Szmukler, G., Kuipers, E., Joyce, J., Harris, T., Leese, M., Maphosa, W. & Staples, E. (2003) An exploratory randomised controlled trial of a support programme for carers of patients with psychosis. **Social Psychiatry & Psychiatric Epidemiology**, 38, pp.411-418.

Szmukler, G.I., Herrman, H., Colusa, S., Benson, A. & Bloch, S. (1996) A controlled trial of a counselling intervention for caregivers of relatives with schizophrenia. **Social Psychiatry and Psychiatric Epidemiology**, 31 (3-4) June, pp.149-155.

Tabachnick, B.G. & Fidell, L.S. (2001) **Using multivariate statistics**. 4th edition. Boston, Allyn and Bacon.

Tarrier, N. (1991) Some aspects of family interventions in schizophrenia: I. Adherence to intervention programmes. **British Journal of Psychiatry,** 159 (4) October, pp.475-480.

Tarrier, N., Barrowclough, C., Haddock, G. & McGovern, J. (1999) The dissemination of innovative cognitive-behavioural psychosocial treatments for schizophrenia. **Journal of Mental Health,** 8 (6) December, pp.569-582.

Tarrier, N., Barrowclough, C., Porceddu, K. & Fitzpatrick, E. (1994) The Salford Family Intervention Project for schizophrenic relapse prevention: five and eight-year accumulating relapses. **British Journal of Psychiatry,** 165 (6) December, pp.829-832.

Tarrier, N., Barrowclough, C., Vaughn, C., Bamrah, J., Porceddu, K., Watts, S. & Freeman, H. (1989) Community management of schizophrenia: a two year follow-up of a behavioural intervention with families. **British Journal of Psychiatry,** 154 (5) May, pp.625-628.

Tarrier, N., Beckett, R., Harwood, S., Baker, A., Yusopoff, L. & Ugareburu, I. (1993) A trial of two cognitive-behavioural methods of treating drug-resistant residual psychotic symptoms in schizophrenic patients I. Outcome. **British Journal of Psychiatry,** 162 (4) April, pp.524-532.

Tausig, M., Fisher, G.A. & Tessler, R.A. (1992) Informal systems of care for the chronically mentally ill. **Community Mental Health Journal**, 28 (5), pp.413-425.

Teichman, Y. (1973). Emotional comparison and affiliation. **Journal of Experimental Social Psychology**, 9 (6) November, pp.591-605.

Telles, C., Karno, M., Mintz, J., Paz, G., Arias, M., Tucker, D. & Lopez, S. (1995) Immigrant families coping with schizophrenia. Behavioural family intervention vs. case management with a low-income Spanish-speaking population. **British Journal of Psychiatry,** 167 (4) October, pp.473-479.

Test, M.A. & Stein, L.I. (1980) Alternatives to mental hospital treatment and social cost. **Archives of General Psychiatry**, 37, pp.409-412.

The Standards of Reporting Trials Group. (1994) A proposal for structured reporting of randomized controlled trials. **Journal of the American Medical Association**, 272 (24) December, pp.1926-1931.

Thoits, P.A. (1985) Social support and psychological well-being: theoretical possibilities. In: Sarason, I.G. & Sarason, B., eds. **Social support: theory, research and application**. The Hague. Netherlands, Martinus Nijhof. pp.51-72.

Thornicroft, G. & Susser, E. (2001) Evidence-based psychotherapeutic interventions in the community care of schizophrenia. **British Journal of Psychiatry,** 178 (1) January, pp.2-4.

Tingey, R.C., Lambert, M.J., Burlingame, G.M. & Hansen, N.B. (1996) Clinically significant change: practical indicators for evaluating psychotherapy outcome. **Psychotherapy Research**, 6 (2) Summer, pp.144-153.

Tones, K. & Tilford, S. (2001) **Health education: effectiveness, efficiency and equity**. 3rd edition. Cheltenham, Nelson Thornes.

Toseland, R. W. & Rossiter, C. M. (1989) Group interventions to support family caregivers: a review and analysis. **Gerontologist**, 29 (4), pp.438-448.

Toseland, R.W., Rossiter, C.M. & Labrecque, M.S. (1989) The effectiveness of pre-led and professionally led groups to support family caregivers. **Gerontologist,** 29(4), pp.465-471.

Treasure, J., Murphy, T., Szmukler, G., Todd, G., Gavan, K. & Joyce, J. (2001) The experience of caregiving for severe mental illness: a comparison between anorexia nervosa and psychosis. **Social Psychiatry & Psychiatric Epidemiology**, 36 (7) July, pp.343-347.

Tseng, W.S., Qin-Yun, L. & Yin, P.Y. (1995) Psychotherapy for the Chinese: cultural considerations. In: Lin, T.Y., Tseng, W.S. & Yeh, E.K. eds. **Chinese societies and mental health.** Hong Kong. Oxford University Press. pp.281-294.

Tsu, J. & Tseng, W.S. (1991) **Culture and family therapy: problems and therapy.** New York, Haworth Press.

Tuckett, A.G. (2005) Rigour in qualitative research (Part II): complexities and solutions. **Nurse Researcher**, 13 (1), pp.29-42.

Turnbull, J.E., Galinsky, M.J., Wilner, M.E. & Meglin, D.E. (1994) Designing research to meet service needs: an evaluation of single-session groups for families of psychiatric inpatients. **Research on Social Work Practice**, 4(2) April, pp.192-207.

United States Department of Health & Human Services (1999) **Mental health: a report of the surgeon general.** Rockville, MD, Centre for Mental Health Services & National Institute of Mental Health, U.S. Department of Health & Human Services.

Ustun, T.B. (1999) The global burden of mental disorders. **American Journal of Public Health**, 89, pp.1315-1318.

Vaughan, K., Doyle, M., McConaghy, N., Blaszczynski, A., Fox, A. & Tarrier, N. (1992) The Sydney Intervention Trial: a controlled trial of relatives' counselling to reduce schizophrenic relapse. **Social Psychiatry and Psychiatric Epidemiology,** 27 (1) January, pp.16-21.

Waltz, C.F., Strickland, O.L. & Lenz, E.R. (2005) **Measurement in nursing and health research**. 3rd edition. New York, Springer.

Warner, R. & De Girolamo, G. (1995) **Schizophrenia.** Geneva, World Health Organisation.

Wasserman, H. & Darforth, H.E. (1988) **The human bond: support groups and mutual aid.** New York, Springer Publications.

Watkins, M. (2001) Providing community care to individuals with mental health problems. In: Hyde, V. ed. **Community nursing and health care: insights and innovations.** London, Arnold. pp.69-94.

Wearden, A.J., Tarrier, N., Barrowclough, C., Zastowny, T.R. & Rahill, A.A. (2000) A review of expressed emotion research in health care. **Clinical Psychology Review,** 20 (5) August, pp.633-666.

Weiden, P.J., Aquila, R., Emanuel, M. & Zygmunt, A. (1998) Long-term considerations after switching anti-psychotics. **Journal of Clinical Psychiatry**, 59 (suppl. 19), pp.36-49.

Weiden, P.J. & Olfson, M. (1995) Cost of relapse in schizophrenia. **Schizophrenia Bulletin**, 21 (3), pp.419-429.

Weiss, H. & Greene, J. (1992) An empowerment partnership for family support and education programs and evaluations. **Family Science Review**, 5 (2), pp.131-148.

Westberg, J. & Jason, H. (1996) **Fostering learning in small groups: a practical guide**. New York, Springer.

Wheelan, S.A. (1994) **Group processes: a developmental perspective.** Boston, Allyn and Bacon.

Wiedemann, G., Hahlweg, K., Muller, U., Feinstein, E., Hank, G. & Dose, M. (2001) Effectiveness of targeted intervention and maintenance pharmacotherapy in conjunction with family intervention in schizophrenia. **European Archives of Psychiatry and Clinical Neuroscience**, 251 (2), pp.72-84.

Williamson, G.R. (2005) Illustrating triangulation in mixed-methods nursing research. **Nurse Researcher**, 12 (4), pp.7-18.

Wills, T.A. & Fegan, M. F. (2001) Social networks and social support. In: Baum, A., Revenson, T.A. & Singer, J.E. eds. **Handbook of Health Psychology**. Mahwah, NJ, Lawrence Erlbaum Associates. pp.209-233.

Wilson, J. (1995) **How to work with self-help groups: guidelines for health professionals.** Aldershot, UK, Arena.

Winefield, H., Barlow, J. & Harvey, E. (1998) Responses to support groups for family caregivers in schizophrenia: who benefits from what? **Australian and New Zealand Journal of Mental Health Nursing**, 7 (30) September, pp.103-110.

Winefield, H.R. & Harvey, E.J. (1993) Determinants of psychological distress in relatives of people with chronic schizophrenia. **Schizophrenia Bulletin,** 19, pp.619-625.

Winefield, H.R. & Harvey, E.J. (1994) Needs of family caregivers in chronic schizophrenics. **Schizophrenia Bulletin**, 20, pp.557-566.

Winefield, H.R. & Harvey, E.J. (1995) Tertiary prevention in mental health care: effects of group meetings for family caregivers. **Australian and New Zealand Journal of Psychiatry**, 29, pp.139-145.

Wituk, S., Shepherd, M.D., Slavich, S., Warren, M.L. & Meissen, G. (2000) A topography of self-help groups: an empirical analysis. **Social Work**, 45 (2) March, pp.157-165.

Wolff, N. (2000) Using randomized controlled trials to evaluate socially complex services: problems, challenges and recommendations. **Journal of Mental Health Policy and Economics**, 3, pp.97-109.

Wolff, N. (2001) Randomised trials of socially complex interventions: promise or peril? **Journal of Health Services & Research Policy**, 6 (2), pp.123-126.

Wong, D. & Chan, C. (1994) Advocacy on self-help for patients with chronic illness: the Hong Kong experience. In: Lavoie, F., Borkman, T. & Gidron, B. eds. **Self-help and mutual aid groups: international and multicultural perspectives**. New York, Haworth. pp.117-140.

Woods, N.F., Haberman, M.R. & Packard, N. J. (1993) Demands of illness and individual, dyadic and family adaptation in chronic illness. **Western Journal of Nursing Research,** *15* (1), pp.15-30.

Wright, E. (1998) The social network context of caregiving in mental illness. **Research in Community and Mental Health**, 9, pp.227-250.

Xiong, W., Philips, M.R., Hu, X., Wang, R., Dai, Q., Kleinman, J. & Kleinman, A. (1994) Family-based intervention for schizophrenic patients in China. A randomised controlled trial. **British Journal of Psychiatry**, 165 (3) September, pp.239-247.

Yalom, I.D. (1998) **The Yalom reader: selections from the work of a master therapist and storyteller.** New York, Basic Books.

Yalom, I.D. (1995) **The theory and practice of group psychotherapy.** 4th ed. New York, Basic Books.

Yang, L.H. & Pearson, V.J. (2002) Understanding families in their own context: schizophrenia and structural family therapy in Beijing. **Journal of Family Therapy**, 24, pp.233-257.

Zastowny, T.R., Lehman, A.F., Cole, R.E. & Kane, C. (1992) Family management of schizophrenia: a comparison of behavioural and supportive family treatment. **Psychiatric Quarterly,** 63 (2) Summer, pp.159-186.

Zhang, M., Wang, M., Li, J. & Philips, M.R. (1994) A randomized controlled trial of family intervention for 78 first-episode male schizophrenic patients: an 18-month study in Suzhou, Jiangsu. **British Journal of Psychiatry,** 165 (Suppl 24) August, pp.96-102.

Zimmerman, M.A. (1990) Taking aim on empowerment research: on the distinction between the psychological and individual conceptions. **American Journal of Community Psychology**, 18 (1) February, pp.169-177.

Zimmerman, M.A. (1995) Psychological empowerment: issues and illustrations. **American Journal of Community Psychology**, 23 (5) October, pp.581-599.

Zimmerman, M.A., Israel, B.A., Schulz, A. & Checkoway, B. (1992) Further explorations in empowerment theory: an empirical analysis of psychological empowerment. **American Journal of Community Psychology**, 20 (6) December, pp.707-727.

Zola, I.K. (1991). Bringing our bodies and ourselves back in: Reflections on a past, present, and future 'Medical Sociology'. **Journal of Health and Social Behaviour**, 32 (1) March, pp.1-16.

APPENDIX 1 SEARCH STRATEGIES TO IDENTIFY RESEARCH LITERATURE ON FAMILY INTERVENTION FOR PEOPLE WITH SCHIZOPHRENIA

A literature search was undertaken between October 2004 and December 2005 to identify all published research literature and systematic reviews relating to the use of family intervention in schizophrenia. A broad range of electronic bibliographic databases in medicine, health care, nursing, psychology, and social sciences were searched from 1985 - 2005. Starting my literature search in 1985 was mainly because from the mid 1980s onwards, there were an increasing number of research studies and controlled trials of family interventions and the findings of these studies have established a more sound evidence base on the effect of family environment and family-focused intervention for schizophrenia (Pharoah et al., 2001). Earlier citations were followed up and citation and author searches of the most central works in this subject were carried out. The searches were restricted to English language and included all brief and full research reports. These databases were:

1. American College of Physicians (ACP) Journal Club (1991 – December 2005)
2. CINAHL (1985 – December 2005)
3. Cochrane Central Register of Controlled Trials (1985 - 2005)
4. Cochrane Database of Systematic Reviews (1985 - 2005)
5. Embase (1985 - 2005)
6. Medline (1985 - 2005)
7. NHS Database of Abstracts of Reviews of Effects (DARE)
8. Ovid (full text, 1990 – 2005)
9. PsycINFO (1985 - 2005)
10. Social Sciences Citation Index (1985 – 2005)

Some broad search terms relating to psychosocial intervention and their permutations (e.g. psychosocial intervention, family intervention, family treatment, psychotherapy, and mental illness) were used initially to identify all possible relevant articles to family intervention. The search results were combined with the terms 'schizophrenia' and 'evaluation' or 'effect'. The publications from 1985 onwards were thus identified, with no restrictions on language and study or publication type. A sample search strategy (in Ovid biomedical and health care database) is provided

below in a table. This preliminary search yielded a large number of research articles and a few literature or systematic reviews; and a total of 338 articles were identified. Titles and abstracts of these retrieved articles were scrutinised to check whether they were relevant and appropriate to the topic of this review. Studies were included if they met the following criteria:

(a) At least 50% of participants were adults aged 18 years and above with a diagnosis of schizophrenia;

(b) Patients primarily diagnosed with schizophrenia and co-morbidity of other mental illnesses such as substance use and depression allowed;

(c) Psychosocial interventions were conducted for family members on either an individual or group basis, including or excluding the patient, and did not restrict to an in-patient context;

(d) Studies were primary research, experimental or quasi-experimental studies assessing the psychosocial health outcomes of patients and/or their families, before and after an intervention;

(e) Studies were systematic review and critical review of literature on family interventions for people with schizophrenia.

Cited references of the included studies were also retrieved from the electronic databases and by hand searching in the university libraries and checked for their appropriateness to this literature review. Citation searches were performed on key authors and papers, identified from the electronic databases search, in the Social Sciences Citation Index. Finally, this search generated 102 articles for inclusion, of which 75% of them (65 articles) were published in last 10 years (1996 to 2005). Seven of them were literature review or systematic review of family intervention or psycho-education intervention for families of people with schizophrenia (e.g. Barbato & D'Avanzo, 2000; Dixon et al., 2001; Pharoah et al., 2001). The articles included were also categorised into those containing outcomes for both patients and family carers (48 articles) and those containing mainly outcomes for patients only (54 articles). All of these articles were written in English language.

Sample Search Strategy in Ovid Health Care Database

Step	Search term	Number of articles retrieved
1	psychosocial intervention$.tw.	2329
2	mental ill$.tw.	21146
3	family intervention$.tw.	1053
4	family treatment$.tw.	635
5	family work.tw.	1131
6	psychotherap$.ti.	10073
7	family therap$.ti.	229
8	schizophren$.tw.	25579
9	schizophren$.ti.	5344
10	or/1-7	9285
11	8 and 10	881
12	9 and 10	435
13	evaluat$.ti.	90
14	effect$.ti.	145
15	or/13-14 and 11	60
16	((famil$ or schizophren$) adj3 (intervention$ or therap$ or treatment$)).ti.	1004
17	11 and 16	312
18	limit 17 to English language	307
19	or/13-14 and 18	113
20	limit 19 to English language	102

APPENDIX 2 A SAMPLE SEARCH STRATEGY USED IN OVID MEDLINE (1980 – December 2005)

Step	Search term	Number of articles retrieved
1	schizophreni$.tw.	25089
2	exp mental disorder/	28340
3	exp mental illness/	21086
4	(serious or severe) adj2 (mental ill$).tw.	928
5	psychos$.tw.	37038
6	or/1-5	70529
7	mutual support.tw.	153
8	mutual aid.tw.	108
9	self help.tw.	2002
10	social support.tw.	8249
11	family work.tw.	1131
12	group therap$.tw.	1471
13	family therap$.tw.	1302
14	family intervention$.tw.	404
15	or/7-14	13186
16	6 and 15	397
17	limit 16 to English language	390

APPENDIX 3 SUMMARY OF STUDIES OF MUTUAL SUPPORT GROUP INTERVENTION FOR FAMILIES OF PEOPLE WITH SCHIZOPHRENIA

Study	Country	Sample	Intervention	Method	Instrument	Main Findings
Albramowitz, I.A. & Coursey, R.D. (1989)	US	Four community mental health centres near Baltimore & Washington, DC. 24 subjects in one of five structured educational support groups for family carers of people with schizophrenia; 24 subjects as matched controls. Family carers: 75% parent, >70% women, mean age of 51 years, 31% Black, 3-5 persons living with patient. Patients: 29 men and 19 women, 67% aged between 25 – 35 years, 1 – 30 years of illness.	*Treatment group*: six 2-hour long weekly group sessions, 5 – 17 family carers in each group; group content based on needs assessment. Content of sessions: (1) introduction & initial discussion of current problems; (2) information of the illness and symptoms; (3) patients' coping with symptoms, medication and environment; (4) principles of managing problem behaviours; (5) community support resources; (6) review prior learning and develop action plans. *Control*: routine community mental health care provided by the Centre.	Experimental, pre-test and post-test design, using questionnaire.	State-Trait Anxiety Inventory. Relatives' Stress Scale. Nine-item scale for community resources use. Generalised self-Efficacy Scale.	Results of analyses of covariance indicated that the carers' support group showed significant improvements on personal distress, management of home life, reduction of anxiety, and increase of community resources utilisation. Over 30% of the support group members indicated that the information received, the opportunity to talk to other participants and the community resources were most helpful.

Gidron, B., Guterman, N.B. & Hartman, H. (1990)	Israel	50 parents of chronically mentally ill in five cities of Israel, 32 participated in self-help groups and 18 did not. Family carers: 62% female; 90% married; median age of 61 years (range 41-82 years); 74% European or American born; 24% elementary school and 8% college education; 50% had three or more children. Patients: 60% aged 26-35 years and 20% > 35 years old; mostly schizophrenia with 66% more than 10 years of illness; 50% hospitalised >3 times; 44% lived with parents and 24% lived alone or sheltered home.	Enosh, a national voluntary organisation for family members of the mentally ill, provided support group, legal advices and advocacy services. The support groups primarily engage in emotional support and information of mental illness.	Cross-sectional, national survey using self-report questionnaire. (Participants vs. non-participants)	Subjective Family Burden scale. Perceived intensity of stress (24 items). Perceived use of coping strategies (19 items).	Group participants had higher education level, housing density, and more knowledge of mental illness than non-participants. Group participants with higher socio-economic status reported coping patterns that tended to be both more active and interactive than non-participants. They also reported greater concerns about psychosocial issues such as difficulties accepting the situation, relations with spouse, and guilty feelings about their child.

Kane, C.F., DiMartino, E. & Jimenez, M. (1990)	US	37 of 104 families of patients with chronic schizophrenia or schizoaffective disorder contacted and agreed to participate. Families: 49 individuals from 37 families; 65% female; mean age of 49 years; 92% White; middle and high social class; 84% parent and 14% sibling; average 42 hours with patient per week. Patients: mean age of 26 years; average 4 times of hospitalisation and 6 years since first hospitalisation.	*Short-term, 4-session multifamily education and support groups* were conducted weekly at the psychiatric unit. Each session lasted 2 hours and was led or facilitated by the researchers and graduate students in mental health nursing. *A psychoeducation group using Falloon's model,* consisted of interactive instructional activities. The support group was based on a self-help model, in which members promote change through self-directed reciprocal helping. It consisted of non-structured sessions, in which relatives discussed the impact of the illness on their lives and coping with these problems.	Quasi-experimental, non-equivalent comparison groups, pre-test and post-test design, using questionnaire.	Mental Illness Questionnaire (for knowledge). Perceived Social Support Questionnaire. Family Questionnaire (49 items, for distress and coping). Depression subscale of the Symptom Distress Checklist. Intolerance of ambiguity measure (at pre-test). 8-item Client Satisfaction Questionnaire (at post-test).	33 relatives who completed the post-test were included in data analysis. Analysis of covariance on adjusted post-test means, controlling relative and patient age, indicated that the short-term psychoeducation group had significant greater improvements on depression and satisfaction with group participation than the support group. Both groups improved significantly on knowledge measure over time. Depression at post-test was related to patient behaviour, changes in ability to cope, distress, and satisfaction with group.

McCreadie, R.G., Phillips, K., Harvey, J.A., Waldron, G., Stewart, M. & Baird, D. (1991)	UK	63 relatives of 52 patients with schizophrenia living at home were recruited; Treatment group consisted of 31 relatives (25 patients) who agreed to attend the intervention and the control group consisted of 32 (27 patients) who refused to attend. Finally, 17 relatives (12 patients) were designated the intervention group and 14 relatives failed to attend the intervention. Relatives: 48% (treatment) and 41% (control) male; mainly parent (55% and 53%) and spouse (26% and 41%); 48% (treatment) and 28% (control) high expressed emotion.	Relatives were offered a package of treatment: educational seminars (weekly, one hour, information of the illness and treatment, and led by psychiatrists), *relatives' discussion groups* (weekly, one to 1.5 hours, focused on coping skills, and led by two social workers), and *family meetings* (weekly or biweekly at home, included patients, discussed about everyday problems, and led by one social worker). The treatment group (n=17) attended in average 10 sessions (range 3-20). At least one member of each family had >7 sessions (median=12, range 8-20).	Quasi-experimental, non-equivalent comparison groups, pre-test and post-test design; follow-up for 18 months after intervention.	Expressed emotion (EE) using Camberwell Family Interview. Amount of face-to-face contact in one week. Relapse: number of re-hospitalisation in 18 months before and after intervention and change or increase of antipsychotic medication.	Main reasons for refusal of intervention were: 'things are fine at the moment', 'it's the patient who needs help, not me', and 'the patient doesn't want anyone else to know he has been ill. There was little change in support group participants' level of EE after intervention. Two relatives in high contact were now low, two in low contact high. Number of patients relapsed in the support group was the same in the 18 months before and after intervention, despite total number of relapses fell after intervention. No significant differences on relapse and EE level between groups.

Sheridan, A. & Moore, L.M. (1991)	Ireland	29 parents of 17 young people with schizophrenia were recruited conveniently from an adolescent service at a community psychiatric centre. Parents: 16 couples and 5 individual parents; 72% female. Patients: 41% female; mean age of 19.2 years, ranging from 16-26 years; 59% less than 6 months illness.	*Six-session education and support groups* were conducted 1.5 hours weekly and led by peer members and professionals including social workers, psychologist and psychiatrist from the Adolescent Team at the centre. Content of the sessions included: (1) introduction, (2) four sessions for issues: diagnosis and medication, family issues, illness and its treatment, and prognosis and the future; and (3) establishing social support network, lives outside the family and future personal goals. A follow-up meeting in three months time was conducted to review their personal goals.	Cohort study, pre-test and post-test design using questionnaire.	Three self-designed questionnaires: (1) 7 questions to assess the effects that managing the illness had had on parents (Pre-test only); (2) 17 questions to assess parental levels of knowledge about schizophrenia (Pre-test and post-test); (3) 11 questions to seek feedback on the group participation (Post-test only)	Most participants agreed that they worried too much on the illness; their time to relax and concentration on work were affected; and feelings of worry and sadness were more difficult to express. There were no significant differences on knowledge about the illness before and after intervention. The most useful components were: meeting and listening to others in a similar situation and medical aspects of the illness. The highly rated content by parents of patient with more chronic illness was: prognosis and the future and family issues. They wanted to have more information about coping with illness behaviour.

McCann, G. (1993)	UK	21 relatives or friends of patients in treatment and therapy at Ashworth Special Hospital, Merseyside and they participated in a relative support group there for over one year. There was not any information of their demographic characteristics.	The *relatives' support group* met monthly for 1.5 hours on ward for enhancing their support network. There was an average attendance of eight participants per meeting. The group was facilitated by the ward staff, rehabilitation staff, consultant psychiatrist, and other disciplines. Minutes of each meeting were taken. The meetings were not open to patients, although some meetings had included patients.	Cohort study, retrospective qualitative evaluation using the minutes of meetings and questionnaire.	Qualitative analysis of the minutes of 12 group meetings. A self-designed questionnaire with seven questions to evaluate the group.	From the minutes, care and treatment of patients within hospital and preparation of patients for discharge & after-care were the relatives' most predominant issues (36% of group time). Families felt that they should run the group themselves & requested for a formal link to hospital management. Benefits of group participation included: information of the illness and its treatment, hope and more involvement in patient care. They wanted more staff and patients in the meetings & more support groups in their home areas. They indicated that the minutes of meetings kept them up-to-date about the group.

Turnbull, J.E., Galinsky, M.J., Wilner, M.E. & Meglin, D.E. (1994)	US	55 family members from three adult psychiatric units, self-referred or referred by staff, participated in a short-term social group work intervention for families of psychiatric in-patients. No description of patients and family members' demographic characteristics in the article.	*Social Work Family Education and Support groups* consisted of a few 1.5 to 2-hour group sessions, including didactic teaching and group discussion. The groups were facilitated by one social worker. Teaching included impact of hospitalisation on patient and family; aetiology of mental illness, its treatment and rehabilitation; alliance with staff in treatment plan; treatment modalities; and family role in providing information regarding ill relative. They facilitated discussion of symptoms, medication and approaches of caregiving, & group members continually encouraged to share experiences.	Cohort study, pre-test and post-test design using questionnaire.	Self-designed questionnaire to measure the perceptions of family members in the areas of information (7 items), coping (7 items), and support (7 items). Group interview of four practitioners to gain their perceptions of the experience of participating in the program and of the value of the groups to family members.	The results indicate significant increase of the overall scores and the information, coping and support domains. Significant changes occurred on all items of information and two items related to coping with staff relationships. The participants perceived the group provided support through help, advice and consideration by other group members and staff and that they were able to help others. Practitioners noted that the group offered benefits in terms of its systematic information provision, its ability to help families make supportive network, and its utility in integrating family into treatment process.

Medvene, L.J., Mendoza, R., Harris, N., Lin, K.M. & Miller, M. (1995)	US	32 Mexican American who were Spanish-speaking parents of patients with schizophrenia or schizoaffective disorder, 14 attended a parent support group in Los Angeles and 18 were non-participants in a community mental health agency. Parents: 84% female, mean age of 61 years, 47% married, 63% elementary school education, low family income. Patients: 61% male, 10th grade education, mean age of 33 years, average 6 years of illness and 2.5 times of hospitalisation.	Fourteen parents were recruited from two *Spanish-speaking family support groups*. The groups facilitated by Hispanic, mental health staff consisted of 10 parents and met weekly at the agency. The groups focused on sharing information about their problems in caregiving.	Cross-sectional, comparative design using questionnaire. (Participants vs. non-participants)	Cuellar's 20-item Acculturation Scale. Family Burden Interview schedule. Modified Mental Health Belief scale. 6-item Social Support Questionnaire. Parents' help-seeking preferences (5-point scale). Preferences for organisational arrangements. Brief Psychiatric Rating scale.	Parents' group attendance was significantly related to level of burden experienced; therefore, group participants indicated higher family burden, including concerns about future care of their child and emotional health issues, than non-participants. Group participants were more likely than non-participants to believe their child had a mental illness & less likely to endorse the moral attribution that their child's problems were due to laziness or weakness. Levels of social support were similar between groups. Main sources of support were family members (61%), neighbours (41%) & people related to religion (34%).

Winefield, H.R. & Harvey, E.J. (1995)	Austral-ia	36 of 56 family caregivers of schizophrenia sufferers in the Adelaide metropolitan area, who could attend half of the group meetings. Weekly family discussion groups (two groups, 10-11 families in each group) & a waiting-list control group (n=15). Family carers: mean age of 58.9 years (SD=13.1); 89% woman; 25% employed; 42% married; 86% parents; 61% with high contact patient (2+ days per week). Patients: illness of 1.5 to 35 years duration; no hospitalisation in the last 12 months.	*A series of 8 weekly discussion group* meetings. Content of sessions: (1) introduction, discussion about ground rules & caregivers' worst problems; (2) causes & nature of schizophrenia, medication, and mental health services; (3) early signs of an episode & management; (4) community resources for vocational, accommodation, & guidance; (5) family communication & problem solving; (6) caregiving experience sharing, how to maintain hope and take care of themselves; (7) effective lobbying groups and media use; (8) summary & discussion on the need of follow-up meeting.	Quasi-experimental, non-equivalent groups, one pre-test and two post-tests (immediate and 8 weeks after intervention), using questionnaire. Open-ended questions about family caregivers' responses to treatment group.	Caregivers' support & coping: Multidimensional Support Scale and ten questions about taking care of own well-being. Caregivers' psychological state: Profile of Mood States; Family Attitudes scale. Process of group meetings: audio recordings of group sessions; group attendance and reasons for absences.	Significant increase in availability and adequacy of family and peer support in all the groups during intervention and follow-up. Participants enjoyed attending the group and gained increased confidence from sharing their problems and ideas with others. 79% tried to put into action something they had learned from group & some found it to be successful; 71% experienced positive changes in feelings or behaviour toward patient. Their worst problem were patient's symptoms, lack of services, concerns for future, and family strains. Attendance rate was high once they were engaged.

Mannion, E. & Meisel, M. (1996)	US	225 family members of people with schizophrenia or affective disorder around a large East Coast area, through a network of support groups, hospital social services and information programmes for families of psychiatric patients. Family members: 88% female; 84% white; 56% married and 11% single; mainly high school or college graduates; 87% sibling and child; mean age of 55 years. Patients: 64% schizophrenia; mean age of 36 years and illness duration of 12.7 years; about 50% had substance use or forensic problem; 3-5 times of hospitalisation.	More than half of the family members were a participant in *a family support group or the National Alliance for the Mentally ill.*	Cross-sectional survey by face-to-face interview using questionnaire. (Participants vs. non-participants)	Carver's adaptive coping scale. 15-item patient functioning scale. Norbeck Social Support Questionnaire. Family Burden Interview Schedule. Hatfiled's self-efficacy scale. Pearline and Schooler's Mastery scale. Texas Inventory of Grief.	Logistic regression analysis comparing participants to non-participants indicated that support group participants were more likely to be non-white, more educated, a parent with a relative who had better functioning and had been ill for a longer period of time. They also reported less subjective burden, smaller social network, and greater utilisation of adaptive coping strategies than non-participants. The assumption that people with more severely ill relatives tend to join support groups is challenged by the results.

Heller, T., Roccoforte, J.A. & Cook, J.A. (1997a)	US	131 participants from 12 family support groups for people with mental illness from community service agencies in Chicago and two in Illinois returned the questionnaire. One year later, 96 returned the 2nd set of questionnaire. 59 non-participants were recruited in the service agencies. Family carers: over 75% female and White; 60% married; 49% mother; mean age of 57 and 53 years; about 14 years of education. Patients: 67% male; 50% schizophrenia; mean age of 36 years & onset at aged 20 years; 35% living with family (12% non-participants).	*Family support groups* affiliated to two larger organisations for mental illness: the Alliance of the Mentally Ill and a large service agency in Chicago. They addressed three primary functions: emotional support, information of mental illness and political advocacy. Four groups were led by professionals and 10 led by family members. Group size ranged from 4 to 26 (mean = 13), met monthly or weekly at homes or service agencies. Sessions included time for informal airing of information and feelings and some invited guest speakers.	Longitudinal, non-equivalent groups design measured at two time-points over one-year interval using self-report questionnaire. (Participants vs. non-participants)	Family Support Services Index. Social Provisions Scale. Support group participants: referral sources, reasons for attending, and reasons for leaving group.	Results of logistic regression indicated that support group participants were having the patient living at home, a greater level of assistance required by the patient, and less services use. Reasons for ongoing group attendance included: receiving adequate emotional support, information and education about mental illness, learned how to help the patient, and feel less lonely by talking with others who share similar problems. Reasons for leaving included: not having enough time to attend, no longer helpful, problems with transportation, inadequate leadership, and lack of comfort with others.

Heller, T., Roccoforte, J.A., Hsieh, K., Cook, J.A. & Pickett, S.A. (1997b)	US	131 families of persons with mental illness from 12 support groups in Chicago and Illinois. Family carers: mean age of 57 years, ranged from 25 to 82 years; 76% females; 79% were White; 59% married; average 14 years of formal education; 34% of them lived with patient. Patients: mean age of 37 years, ranged 17-88 years; 68% male; 56% schizophrenia, 15% bipolar disorder; 24% lived alone and 14% in a supervised setting; 11% had paid employment.	*Support groups* met monthly or weekly, at members' homes or service agencies. Mean group size was 13 members.	Cross-sectional, descriptive survey using mailed questionnaire (Group participants only). 80% response rate.	Group benefits Scale. Family Support Services Index. Social Provisions Scale. Level of group involvement: Support Received scale, Support Provided scale, Friendship Development scale. Group structure: Role Differentiation scale.	Social support resources outside the group and support received from and provided by the group were associated with information benefits about mental illness, services and treatment. Group members who benefited most from group participation were those with less perceived support outside group and more support providing and receiving within group. Results of regression analysis indicated that improved relationship with family and patient are predicted by participant's health and provision of support within group.

Solomon, P., Draine, J., Mannion, E. & Meisel, M. (1997)	US	225 of 244 family members recruited through a network of support groups, hospital services and programs for mentally ill & randomly assigned to 3 groups: 66 to individual consultation, 67 to group workshop & 92 to control group. They were primary carers & contacted patient at least once/week. Family members: 88% female; 84% white; mean age of 56 years; 54% college education; middle class; 76% parent, 11% sibling & 6% child. Patients: 64% schizophrenia; average 3-5 hospitalisation, (33% more than 5); mean age of 36 years & illness of 12.7 years; 21% substance abuse.	*Brief individual family consultation*: education and access to services to each family by mental health specialists. The 15-hour consultation consisted of 3 phases: feeling (needs assessment, dealing with feelings & family strengths), focusing (problem solving & education), & finding (developing caregiving skills & access to services). *Group family workshop*: 10 weekly 2-hour sessions facilitated by a trained family member and a mental health specialist. Each session, 30 min. for information giving about mental illness and treatment and 90 min. for coping skills training, with home practice.	Experimental, three-group (Brief individual family consultation, multiple-family workshops and routine care) repeated measures design, using questionnaire.	Family Burden Interview Schedule. Norbeck's Social Support Scale. Stress scale. Unresolved Grief scale (adaptive coping). Hatfield-based Self-efficacy scale.	171 families for final analysis, 42 dropped out during intervention and 12 during 6-month follow-up. No differences of characteristics between dropped subjects and those remained in the study. Only self-efficacy regarding knowledge of illness and its treatment showed significant improvement after intervention in both groups. Repeated measures ANOVA indicated support group had greater improvement in self-efficacy over time compared with brief family consultation. However, post hoc comparisons indicated no significant differences between groups at 6-month follow-up.

Pickett, S.A. & Heller, T. (1998)	US	A total of 131 families, 37 professional-led and 94 family-led group members. Family members: >72% female; mean age of 56 years; mainly parents & siblings, Caucasian & married; average 14 years of education; annual income from US$20,000 to $29,000; >65% not living with patient; average >3 years of group participation. Patients: > 69% male; average age of 35 years, 15 years of illness, & 17 days of hospitalisation in the past 6 months. Professional-led group had more minority members (32% vs. 15%) & parents (78% vs. 59%).	Participants were recruited from four professional-led and 10 *family-led support groups* for families of people with mental illness in Chicago and southern Illinois. Group size ranged from four to 26 participants (13 in average). 12 groups met once per month and two met once per week, at participants' homes or mental health service organisations. Several models were used to structure the groups including an 8-step model adapted from a 12-step approach and casual sharing of information and support.	Quasi-experimental, non-equivalent comparison group design (Professional-led vs. family-led), using questionnaire.	Group Benefits Scale (11-items, information and relationship benefits). Five-item coping ability scale. Participants rated extent of discussion of 10 topics (housing, medication, family members, dealing with professional, patient's problem behaviour, services, financial concerns, coping with emotions, treatment, and advocacy) during meeting.	Independent t-test results indicated that there were no differences between groups on provision of information about the illness and its treatment and improvement of relationship with patient. There were only few differences between the two groups on group content. Professional-led groups placed greater emphasis on patients' behaviour problems and coping with emotions, whereas family-led groups showed more emphasis on advocacy. A joint collaboration between professional & family group leaders that can share both experience and expertise might work best for a family support group.

Winefield, H., Barlow, J. & Harvey, E. (1998)	Austral -ia	From 36 group members who were caring for a relative with schizophrenia, eight from extreme positions on four intake criteria: (1) length of time since patient's diagnosis; (2) amount of carer-patient contact; (3) level of psychological distress; and (4) level of rejecting attitudes to patient. Family carers consisted of six mothers, one father, and one spouse.	Three series of *eight-session discussion-based support groups*, with topics: (1) introduction and listing of carers' worst problems; (2) update on psychiatric models and medication regarding schizophrenia; (3) recognition of early warning signs of relapse; (4) rehabilitation, accommodation, and other community resources; (5) family communication and problem solving; (6) how carers care for themselves and maintain hope; (7) how to lobby for resources; and (8) the Clubhouse rehabilitation model, summary and follow-up plans.	Qualitative data collected during group sessions.	Participants' responses to group participation, comments on both short and long-term effects, and suggestions on how groups might be selected and structured for maximum effectiveness.	While all carers wanted adequate mental health services, accurate information regarding the illness and respect from health professionals, their length of caregiving experience affected their responsiveness to the discussion topics. In short-term, the carers' most important needs addressed by the group were: availability of mental health services, knowledge of effects of medication and patient's mental health problems, and support from professionals. In long-term, greater sense of control in caregiving and less burden could be found on frequent and consistent participation.

Citron, M., Solomon, P. & Draine, J. (1999)	US	202 family members, including 163 parents (81%), 19 siblings, 10 spouses and 5 adult children, of severely mentally ill people who were members of seven chapters of the Alliance for the Mentally Ill. Family carers: white middle class female (96%), mean age of 60 years; 51% college education; 41.6% lived with patient; 80% had >1 year of participation & 75% on a monthly basis. Patients: 61% schizophrenia & 18% bipolar disorder; 67% male; mean age of 36 years; average 16 years of illness and 31 days of hospitalisation in the past year.	The *family support groups* were *affiliated with the Alliance for the Mentally Ill* and led by one or more elected leaders (families). They met monthly at the service agency, with the fundamental assumption that families do not 'cause' schizophrenia and other mental illnesses.	Cross-sectional, survey design using mailed self-report questionnaire. (Group participants only)	A scale of caregivng duties (2 items). Rating of disturbing behaviours (1 item). Length of membership and intensity of participation in support group. Mechanisms of Change/ Helpfulness (13 items). Group Benefits scale (15 items).	Greatest perceived benefits of group participation were: having more knowledge about mental illness & services, & feeling less alone with their concerns. 20% of participants reported somewhat less able to meet patient's needs & felt more overwhelmed by patient. Results of hierarchical regression indicated that the participants who felt information provision or gaining support and self-understanding from the group process was helpful and those were longer term participants in group (not intensity of participation) were more likely to perceived benefits from group participation.

Cook, J.A., Heller, T. & Pickett-Schenk, S.A. (1999)	US	120 parents, 86 participated in 14 National Alliance for the Mentally Ill-affiliated support groups and 34 non-participants. Parents: 77% mothers, mean age of 62 years, 80% Caucasian and 7% were Native American; 62% married; average education of 13.6 years; mainly middle-class; 32% residing with patient. Patients: 73% male; mean age of 33 years; average 14 years of illness; 53% schizophrenia, 20% bipolar disorder and 32% others such as major depression; 16 days of hospitalisation in the past 6 months.	Four professional-led and 10 *family-led support groups*. Group size ranged from 4 to 26 members, with an average of 13. Participants attended groups for an average of 46 months, and met weekly or monthly at homes or social service agencies. All groups included time for sharing of information and feelings, and guest speakers on some topics. Non-participants were cared by community agencies serving people with severe mental illness.	Cross-sectional, comparative design using questionnaire. (Participants vs. non-participants)	Index of Depression. Social Provisions Scale. Family Support Services Index. Thresholds Family Burden Scale (brief version).	Results of regression analyses indicated that caregiver burden was significantly lower among support group participants, those with lower depression, and those whose patient had fewer unmet needs and days of hospitalisation. Support group participants reported lower levels of formal service utilisation than non-participants.

Pickett-Schenk, S.A., Cook, J.A. & Laris, A. (2000)	US	424 of 1131 participants completed the JOH programme and returned the questionnaire mailed to them. Family carers: 79% female; 92% White; mean age of 56 years; 63% college education; 65% parents; 35% had received prior family education or supporting services; 30% lived with patient; average US$40,001 – 50,000 per year. Patients: 67% male, mean age of 37 years; 42% schizophrenia, 26% bipolar disorder, and 16% schizoaffective disorder; average 21 years of illness & 6 times of hospitalisation.	*The Journey of Hope (JOH) programme* was a family-led education programme for families of people with mental illness offered by the National JOH Institute, the National Alliance for the Mentally Ill. It consisted of a 12-week education course and/or an ongoing support group. 47% of them participated in both education course and support group.	Cross-sectional, survey design using mailed questionnaire. (Group participants only)	Client Satisfaction Questionnaire (8 items). JOH Outcome Survey (15 items; knowledge and morale scales).	The results indicated that the majority of participants perceived substantial increase in their knowledge of the causes and treatment of illness, their knowledge of mental health services and in their morale. Hierarchical regression analyses found that the programme outcomes (satisfaction, knowledge, service use, and morale) were predictive of one another. JOH therefore may provide families with the knowledge and support they need to strengthen their ability to cope with patient care.

Montero, I., Asencio, A., Hernandez, I., Masanet, M. J., Lacruz, M., Bellver, F., Iborra, M. & Ruiz, I. (2001)	Spain	87 patients with schizophrenia and their relatives were referred to the programme by their psychiatrists. 41 were assigned at random to an Relative Group and 46 to single-family home-based Behavioural Family therapy. Families: 56% had >35 hours/week patient contact; 49% high expressed emotion level; 46% had three or more relatives at home. Patients: 67% male; mean age of 26.8 years; 89% single; 72% primary school education; 82% unemployed; average 5.5 years of illness; mean age at onset of 21 years.	*Relative Group* was developed on the basis of studies of expressed emotion. It consisted of two educational sessions at health centre and a few sessions for problem solving, control of expressed emotion, expanding social network, and lowering expectation, followed by weekly 90-minute discussion group, with 8-10 members, facilitated by two therapists. *Behavioural Family Therapy* used Falloon's behavioural framework on single family. It composed of 3 modules: family education about the illness, communication skills training, and teaching & practice of problem solving techniques.	Experimental, equivalent control group design using questionnaire	Psychiatric Assessment Scale. Severity of Symptoms (PAS). Disability Assessment Scale. Knowledge about Schizophrenia Inventory. General health Questionnaire (28 items). Camberwell Family Interview schedule. Medication compliance.	52 (60%) completed the programmes. Both interventions had significant effects on psychotic symptoms, medication compliance, social adjustment, expressed emotion, and knowledge about the illness. Greater improvements in the Behavioural group on: symptoms of delusions and thought disorder, medication compliance, social adjustment (self-care, leisure, household activities, job interest, and family relationships), reduction in critical comments and emotional over-involvement, and increase in positive comments.

Chou, K.R., Liu, S.Y. & Chu, H. (2002)	Taiwan	84 primary family caregivers of a relative with schizophrenia, randomly selected and assigned in support or control group three times from volunteers recruited through information from community agencies, social services, visiting nurses and home health agencies, or self-referrals through media. Family carers: 69% and 63% female; 63% and 66% parents; 20-40% time caring for patient; mainly middle class. Patients: mean BPRS score of 9.6 and 10.1; average 10.9 and 9.2 years of illness.	A *nurse-facilitated support group* consisted of eight 1.5-hour sessions on each Saturday. Zarit et al.'s Caregiver Support Group Procedure Manual was used. Discussion mainly included: information, problem solving, coping and support. Group content was: (1) introduction and orientation; (2) caregivers' emotion and feelings toward caregiving; (3) patients' reactions and behaviour problems to illness; (4) taking care of self and doing positive things with patient; (5) information about community resources, financial issues, in-home services & medical needs; (6) review and future plans.	Quasi-experimental, time series non-equivalent control group design. Subjects completed a questionnaire at baseline, immediate after and one month after intervention.	Caregiver Burden Inventory. Beck Depression Inventory. Physical Self-Maintenance Scale. Instrumental Activities of Daily Living. Caregiving Self-efficacy Scale Brief Psychiatric Rating Scale (Pre-test only). Participants' perceived benefits questionnaire (for support group participants only)	The results indicated that the family support group showed significantly greater improvements in depression, and caregiver burden over time, than the control group. Participants indicated satisfaction with support group experiences and perceived the group very helpful, especially having someone listen to their concerns, helping them with emotional feelings about the illness; and providing information and learning strategies to cope with the situation.

Lemmens, G.M., Wauters, S., Heireman, M., Eisler, I., Lietaer, G. & Sabbe, B. (2003)	Belg-ium	12 family carers and 10 patients of different types of severe mental illnesses such as major depression and schizoaffective disorder, in two family discussion groups of a psychiatric day clinic. Carers: mainly spouse and mother; Patients: 6 female and 4 male; mean age of 34 years.	*Family discussion groups*, each with four to six patients and their families, were conducted over a two-year period. The groups consisted of five to six biweekly sessions and each session lasted about 1.5 hours. A systemic multiple family therapy model was used, with major focus on families' coping and problem solving strategies, impact of the illness on family, family interactions and belief systems, and available resources and family life-cycle issues.	Qualitative exploratory study using questionnaire. Questionnaires were completed independently by family members, therapists and group observers.	Open-ended questions exploring perceptions of therapeutic factors in groups, and specific experiences that the participants considered helpful for individual, family and the group.	The results showed that the therapeutic team and the families diverged in their overall perception of which factors were important in family discussion group. The therapeutic team indicated that the relational climate and structural aspects of the group (group involvement and support from the group), and the specific therapeutic interventions as more helpful than the families. The process aspects in the group members (the experiencing of communality and gaining insight) were, on the other hand, more frequently emphasised by the families.

Szmukler, G., Kuipers, E., Joyce, J., Harris, T., Leese, M., Maphosa, W & Staples, E. (2003)	UK	With stratified randomisation based on patients' diagnoses and carers' relationship with patient, 61 (62%) family carers of patients with psychotic disorders were recruited; 26 randomly assigned to intervention and 23 to standard care. Family carers: 82% female; 66% white & 30% black; 62% parent, 10% spouse & 13% siblings; mean age of 54 years; 46% employed; 18% received college education; 71% had >1 family member with mental illness; 49% lived with patient. Patients suffered from a psychotic disorder, e.g. schizophrenia, schizoaffective or bipolar disorder.	The *one-year family support programme* consisted of six individual family sessions (patients excluded) followed by 12 bi-weekly relative groups (1.5 hours each) run by a Thorn-trained Community Psychiatric Nurse (CPN). Individual family sessions composed of (1) engagement (and identifying problem), (2) education about the illness & services, and (3) development of effective coping strategies. *Relatives' groups* (10-15 members each) led by 1 peer carer and co-led by 1 CPN consisted of education talk (0.5 hour) in each session, followed by 1-hour discussion of carers' problems.	Randomised control trial of a family support group and standard care; pre-test and two post-measurements (immediately and six months after intervention), using questionnaire.	Measures based on the stress-appraisal-coping model of caregiving: Clinical Interview Schedule. Experience of Caregiving Inventory. Coping with Life Events & Difficulties interview. Self Evaluation & Social Support Schedule. Contextual Severity of Caring Difficulty.	26 carers (87%) in intervention group and 23 (74%) in standard care completed the follow-up. Difficulty in engaging and dropouts imposed limitations on the findings. 23 (89%) had full attendance in individual sessions and 3 had none. 16 (62%) attended half or more relatives' group sessions. There were no significant differences on all outcomes between groups at three measurements. The 2 groups indicated significant positive changes over time, on severity of caring difficulties and effective coping. It is uncertain how carers' needs can be met to reduce the difficulties and distress related to caregiving.

Chien, W.T., Chan, S., Morrissey, J. & Thompson, D. (2005)	H.K.	96 out of 300 family carers of outpatients suffering from schizophrenia in two psychiatric outpatient clinics were recruited randomly from the patient lists and they were assigned randomly to either a psychoeducation (n = 33), mutual support (n = 32) or standard care (n = 31) group. Family carers: 66% - 71% male; monthly family income between US$1280–$3205; mean age 40.6–43.2 years, range 22–60 years; mainly parent, spouse or child. Patients: all schizophrenia; 61-70% male; 59 – 65% secondary school education; age range 20–49 years, mean age 28.8– 0.3 years; medium dosage of antipsychotics and average 2 years of illness.	Mutual support group participants received a bi-weekly 12-session programme of mutual support, facilitated by a trained psychiatric nurse, as well as routine outpatient care. Psychoeducation group received a bi-weekly multiple-family psychological support and educational programme based on McFarlane et al. (1995) over 24 weeks, as well as routine care. Standard care group received the routine psychiatric outpatient care only.	Randomised controlled trial, with a repeated measures three-group design. All three groups were compared 1 week prior to intervention, and 1 week and 6 months following intervention, using structured questionnaires.	Family Assessment Device Family Support Services Index Patients' Specific Level of Functioning Scale Length of re-hospitalisation.	At both post-test periods, multivariate analyses followed by post hoc comparisons indicated that the family carers and patients in the mutual support group reported statistically significant improvements on family and patients' functioning, when compared with their counterparts in the psychoeducation and standard care groups. No significant differences in the service utilisation and patients' re-hospitalisation between groups over the 6-month follow-up period.

APPENDIX 4 MORE UNDERSTANDING ABOUT THE FIVE GROUP PHASES

1. NINE PRINCIPLES TO STRENGTHEN MUTUAL SUPPORT

The following nine principles strengthened mutual help and support and served as a guide to the facilitator and peer leaders in running the group. These principles reflected the demands on families of caring for people with schizophrenia in a non-pathological way (Reissman, 1997). Caring of patients by these family members in the mutual support group refers to specific behaviour, actions and interactions that make the patient feel valued as a person; and the family carers themselves, and also their patients, were not blamed to be responsible for the mental illness and its problematic behaviour. These principles were used in the mutual support group to guide the group interaction and discussion and serve as the ground rules of the group, as recommended by researchers (Wilson, 1995; Schiff & Bargal, 2000). They consisted of:

1.1 All-in-the-same boat

There might be differences among the family caregivers who faced a common difficult situation within the group, but above all, they shared this unity of situation, which was the source of their common pain. Therefore, the participants of this mutual support group, similar to family members caring for another patient population, possessed social homogeneity. They did gain strength as individuals and as a group by coming together and struggling against a common plight and a new way of looking at themselves and how they regarded those outside the group.

1.2 Mutual aid and support

The commonality of situation practically guaranteed empathic feelings flowing among the group members. They needed to care for each other in order to experience release from the horror of the event and the crushing blow of their loss, and the therapeutic effect and understanding of being helped by, and helping. Someone else with the same problem was one of the key strengths of the support group. The facilitator needed to ensure the members to not only centre in their own pain but also to reach out to others in empathic ways (Wilson, 1995).

1.3 Reciprocal demands of giving help and being helped

This productive group culture should be developed, in which there were mutual expectations that the members should risk their real thoughts and ideas, listen to each

other, but put their own concerns aside at times to help another, and so on. Taken together mutual support and mutual demand were powerful forces in helping group members in a dialectical fashion, both giving and caring on the one hand, and expecting oneself and others to work on the other (Powell, 1994). It gave the helpers a sense of control: "I can't be helpless if I can help someone else."

1.4 Self-determination

The group members largely determined social and interpersonal activities within the mutual support group internally. This mechanism allowed a new dimension of participatory democracy to emerge. This self-governance of the group was more with what the individuals had to contribute and involve in the process of helping others in the group (Winefield, Barlow & Harvey, 1998).

1.5 Sharing information and personal assets

Imparting information (factual, psychological or personal) and disclosing personal capacities and success in caring, might be a meaningful way to build mutual trust and a demonstration of people caring for each other. Group building started with the process of locating the assets, skills, and strengths of group members. And these strengths and information giving could then be put to work on individual problems.

1.6 Dialectical process

People (individual members) could have chances to think about the different ideas and different ways of doing things among all the group members, and discuss their pros and cons. And where their affirmations and doubts about a topic or problem could be challenged. Both individuals and the group stood to gain from each other in a dialectical relationship.

1.7 Discussing a taboo area

The shared secret (taboo area) was the basis for the formation of the support group, and the small community of mutual helpers was the source of strength for surmounting an internalized 'scarlet letter'. There could be catharsis, examination of feelings of guilt and shame, expressions of hate and hostility towards patient, grieving over the absence of a needed social relationship, and appraisal of a non-stigmatised helping environment (Galinsky & Schopler, 1995). All of these issues could be

ventilated within the group of similar people who did understand and, beyond those, could help one another regain self-respect and self-esteem.

1.8 Individual problem solving

The mutual support group could serve as a healing agent to help an individual member to deal with his/her own unique troubles. The members or the facilitator became consultants, assuming the roles of supporter (showing empathy), clarifiers (helping to think through a problem), challengers (help to think and do things in new ways), and listeners (show that they care). As a result of what the members learned from the group, they might be able to initiate or work out self-care and problem solving strategies for their own use.

1.9 Behaviour rehearsal

Rehearsal of what had been informed and was going to learn frequently took the form of role-playing. The support group was a safe place to risk some 'run-throughs' of anxiety-provoking social situations, particularly managing patient's problematic and disturbing behaviours. The group could support, guide and offer criticism of the individual's try-outs, which were new or felt insecure to act out in the family life.

2. MORE UNDERSTANDING ABOUT THE FIVE GROUP PHASES

In order to increase the understanding about the phased development of the group, the five phases of the mutual support group are explained in more detail as follows:

Phase 1 - Who we are; we need to share our experiences and feelings

- In the first phase, the group was encouraged to be aware of their common issues of concern (similar life circumstance, facing with the same illness, similar situation and difficulties in caregiving, and so forth). There was a general coming together around these issues with comparisons and an examination of similarities and differences. Thus, the group would inevitably generate a greater awareness of how others managed, or failed to manage their lives. The group and the facilitator might describe the sensitivity that was elicited by the group as an interpersonal relationship, responses to other's attitude and behaviour, and concerns with how

one participant perceived others and how one member was perceived by other group members.

- In this first phase, everyone should also have a chance to tell her story: this is who I am; this is what happened to me, my family, and my ill relative; this is what I have tried or not tried to do about it. These were the 'introductions of myself' to the group. Group members were often reserved in their early verbal contributions, not wanting to reveal too much about themselves, but just enough to make their presence known. What needed was there should be more to come later.
- The making of a good impression, through being careful and circumspect in the beginning stages of the group, was an appropriate social behaviour or recognition - for a more solid self-esteem and the approval of others. There was then much uncertainty and ambiguity in this beginning phase, when members neither knew each other nor had much sense of who the leader was and what they had to offer, except for what they were told about the group in the briefing by the facilitator. Therefore this stage should involve a group exploration of the following items:
  a. Stated the purposes;
  b. Agreement on format, modalities and rules;
  c. Maintenance issues - include meeting time, place, transportation, client care alternatives, and so forth. Whatever support the facilitator could offer to enable member attendance was an asset for group continuity and success.
- In the second session, information giving and sharing between the facilitator and the group members about the mental illness and its symptoms and behaviour was emphasized and encouraged during the group meeting, and thus provide opportunities to clarify some commonly held misconceptions about the illness, e.g. the family inheritance should be the main cause of the illness. Sharing of knowledge and caring experiences by the group members was fully supported, with positive reinforcement and non-blaming attitude.

Phase 2 – Being aware of and accepting our feelings and reactions

- This second phase involved turning to the peer helpers and group members, seeking information and emotional support on one common issue or stress at one time. What should be kept in mind was that the group process and the main purpose of this phase was to some considerable extent shaped, if not determined,

by the agreed-upon format, and thus according to the contents and format of each session being planned at least one week in advance. The typical 2-hour session began with an introduction or a video (information giving about the illness), and is followed by group discussion and interaction (experiential learning).

- The experience of social interactions and support within the group, similar to their social networks outside group, might not be always positive. There were at least three potential barriers which were important for the facilitator and the researcher to understand (Parry, 1994): first, seeking and receiving social support could constitute threatens to one member's self-esteem, particularly when this was the first time the person in need of this help, for fear of rejection, criticism, shame, or of being controlled by others; second, the availability of support could be reduced just when one needed it most; and third, the social network could be a source of stress and personal demand as much as a resource. The facilitator should assist the group to establish positive attitude to seeking help and support during group meetings and nourished the group atmosphere and skills in asking for and receiving help appropriately, using them well and rewarding every member for giving support to others. Through such empowering process, the self-efficacy and willingness to mutual support was fostered.
- The facilitator in dealing with their unresolved psychological disturbances in caregiving introduced strategies of emotion-focusing coping (Greenberg, 2002). This involved efforts to identify intense and maladaptive emotions and regulate these emotional responses to stressful situations especially caregiving and its related issues. The essential method of tackling emotions of the caregivers was the use of group activities that encouraged sharing of emotions and self-perceptions, and those that encouraged feedback from others about their feelings could help the caregivers to view themselves and their situations in ways that reduced stress. For example, learning about the negative feelings of other group members toward an aggressive behaviour of ill relative could lead to a reduction in guilt about one's own anger and resentfulness.
- Sharing information and personal reactions to specific problems and issues about caregiving could also lower the group members' stress through this mutual understanding of strengths as well as weaknesses on caregiving and recognition of 'I'm not the worst unlucky carer in the real world'. For example, a group member

who felt guilty that she was not doing enough for her ill relative might find that she was doing much more than most other caregivers; as a result, she reassessed her situation and might feel better about herself and her performance as a caregiver.

Phase 3 - Understanding ill relatives' needs and available supporting resources

- A strong sense of cohesiveness and mutual support usually developed within the group during this phase. Often members became friends outside of the group and the peer leader or facilitator became less and less prominent. Unity among the group members grew when these strangers joined together, experiencing the universality of their feelings and vulnerabilities amidst a supportive community of people with similar situations. At this period, members tapped into the healing aspects of decreasing self-focus and greater helping of one another. Each member would talk about his/her ill relative's needs and the available community resources useful to them in caring the relative.
- Some dependence upon the facilitator and the veterans in the group were required by the group members for some useful information about the illness, strategies of coping and caregiving, and helping resources in caring their relative.
- Sharing of their real stories or experiences further enriched their understanding of their strengths and weaknesses and accepted their situation similar to others. Learning from others to interact with the patient was very important to reduce their stress in caring for the patient and to live with the patient harmoniously. Applying these communication skills learned from the group sessions into the daily living could provide chance for each family to experience small success, as well as failure with adequate support and advice for further improvement from the other group members.
- Group members were also encouraged and assisted to examine their perceptions of being supported or unsupported at then end of each group meeting and identified social interactions in which provision of psychological, informational or instrumental support was devalued and rejected, or on the other hand abused and being over-dependent. This was important for the family caregivers to learn from the group experience the value of the reciprocating support and appreciate or accept that real but less than perfect helping behaviour within the group.

Phase 4 – Adopting new roles and challenges in caregiving

- Members were able to examine their own characteristics in dealing with a particular life stress. The self-examination typically involved an identification of one's own problem solving techniques and coping styles and the naming of specific anxieties. This stage often represented a more frank communication of the stories recounted in phases 1 and 2. Members might examine their own behaviour patterns and ways of thinking and feeling, and how these influenced their responses and choices; but this process did not occur with the intensity of interpersonal and intra-psychic analysis characteristic of psychotherapeutic groups.
- Success in this phase facilitated the group member to receive the difficult life situations as challenges and positive experiences, and contributed to a smooth progression towards very deep cohesiveness; that is completely open and honest communication and sharing propelled the process on and towards the final stage.
- The problem solving approach was also introduced for coping members' individual difficult situations of caregiving, that included seven steps (Hurst, 1993):

a. Problem identification;
b. Generation of alternative solutions;
c. Examination of strengths and weaknesses of each alternative;
d. Individual cognitive rehearsal of the action plan and discussion among group members;
e. Execution of the plan in caregiving;
f. Evaluation of the plan in next group meeting.

- The use of problem-focused strategies in meeting the mentally ill relative's ongoing demands was found to minimize family conflicts and personal burden (Solomon & Draine, 1995; Lefley, 1996). In each week, the group participants have the opportunities to discuss and work on individual problems of caregiving using this strategy.

Phase 5 – Conclusion: Where will I go from here?

- Instead of dependence upon experts, the members functioned in mutually helpful interrelationships. While a supportive atmosphere was nurtured throughout the group's life, the mutual aid system only reached maturity in this phase. The members required using the learned knowledge and skills to continue their caregiving and extend the supporting network to people outside this group by using

the culture of helping each other. Some members might continue in touch with other group members for support or organizing the group meetings by themselves. This was encouraged and assisted by the facilitator, such as exchange of contact information and suggesting some venues for social gatherings and further meetings.

- Similar to traditional termination period of a group, the focus of the fifth stage was to assure support and coping beyond the group's ending. However, the psychological preparation of separation was started in the fourth phase, in which the participants were reminded of the group termination and encouraged to talk about their feelings and possibility of continuation of the group support. The process of termination could take many forms, such as:
  - Arranging reunion or check-in meetings of the group;
  - Forming dyadic supportive relationships or buddy-type systems;
  - Evolving the support group into a long-term self-help group, or members joining an established mutual support group;
  - Linking members with pre-existing community supports and services; and
  - Reviewing available crisis services or agreements around contact with group members.
- This recognition of the need for continuity in the support network was fundamental to support theory and epitomized the mutual aid process. This final phase was viewed more as a period of transition rather than termination. The group members might decide any follow-up care and services they needed, the facilitator then reviewed the available social and supporting services and assisted them to access those helping resources.
- Finally, the facilitator needed to explain the follow-up procedure of this study:
  - Three post-test measurements: one week, half year and one year after the intervention;
  - An semi-structured interview for some of the family members one to two weeks after the intervention;
  - Telephone follow-up of family condition monthly for one year.

APPENDIX 5 OBJECTIVES & ACTIVITIES OF THE TRAINING WORKSHOP FOR GROUP FACILITATOR

Three-day Training Workshop for Group Facilitator

A 3-day training workshop was conducted for the group facilitator in this study, and would be useful as a reference for other nurses and health professionals who plan to work as facilitators of family support groups for mental illness. This workshop aimed to help the facilitator understand how to assist and collaborate with the family mutual support group, grounded with the rationale that people can obtain best support and information to cope with caregiving situations from those who have already gone through a similar experience (Wilson, 1995). The contents of the workshop were largely derived from the practical experience and guidelines reported by Atkinson and Coia (1995), Westberg and Jason (1996) and Gazda, Ginter and Horne (2001). The workshop provided important and essential information, techniques and principles about the establishment, facilitation and evaluation of a mutual support group, via critiques of videotapes about simulated family group meetings, mini lectures to elicit information about the family support group planned by the researcher, discussions on principles, guidelines and checklists for working with a family support group. The main themes of the workshop are:

Day 1: Understand mutual support group and your attitude to group work

Day 2: Learning from group experience and establishing techniques in facilitation of a support group

Day 3: Advanced skills of group facilitation, practice of family interview and review of learning to be a facilitator

Main Contents:

Day 1: Understanding of mutual support group and your attitude to group work

The first day of the workshop was mainly focused on the introduction of mutual support group and its key elements to the facilitator and the recognition and clarification of the facilitator's values and attitude to the future group work. In the morning session, the main activities included: briefing of the purpose and design of the study, and the structure, characteristics and functions of a mutual support group; discussion about the characteristics of the mutual support group in this study to families caring for a patient with schizophrenia, in terms of psychological support,

sharing information, knowledge acquisition, and practical advice and help, and its potential positive effects and limitations.

In the afternoon session, the facilitator was encouraged to examine his personal values that might influence his attitude to a mutual support group. The researcher invited an experienced group therapist to speak on the common goals/targets of a mutual support group for families of mentally ill people, and the basic principles and techniques in working with a family group; this was then followed by a group discussion of the challenges and difficulties in working with a support group among the researcher, therapist and facilitator.

Day 2: Learning from group experience and establishing techniques in facilitation of a support group

During the second day, a video about how to talk to families of patients with schizophrenia was shown to the facilitator. This video illustrated the problems encountered by health professionals who have contact with these families. Discussion was then made to understand the importance of being knowledgeable and skilful in communicating with one family and families in groups. After that, some updated references and reading materials relating to aetiology, treatment and research of schizophrenia were introduced.

In the afternoon, the facilitator was arranged to participate and observe a one-hour meeting of an existing family support group conducted by a community psychiatric nurse at an outpatient clinic in another geographical region. The facilitator discussed with the community nurse and two members of the group about the important issues on the process, approaches of helping and sharing, interaction skills observed during the meeting. It was invaluable for the facilitator to take this opportunity to learn about the development and process of a mutual support group from the experience of the nurse leader and the group participants. Finally, the researcher consolidated the learning experience with the facilitator and explained to him about the main contents, approach, and protocol of the support group used in this pilot study.

Day 3: Advanced skills of group facilitation, practice of family interview and review of learning to be a facilitator

During the third day, the experienced group therapist was invited again to teach

some advanced skills in facilitation of a family group, which included: the role and degree of involvement of a group facilitator in the group process; the techniques for encouraging group members to actively involve and attend the group; the ways to offer support, advice, information, resources, and referrals to group members; and the importance of directive and non-directive interventions. A discussion was then carried out to understand and appreciate the importance of confidentiality, when and how to achieve this, and recognize some dilemmas and difficulties of various kinds are in integral part of this group work, to be identified and faced.

The last part of the morning session was to review the learning objectives of this workshop to be a support group facilitator and they included:

- To appreciate an enabling and empowering approach of family care in group;
- To be aware of some constraints of good practice, e.g. traditions of professional authority and knowledge, conflicts of interest, and unpredictable nature of the mutual support group;
- To recognise how everyone, including the families, patients and facilitator, can benefit and grow when the group works well;
- To recognise the support from the researcher in resolving problems during group facilitation.

In the afternoon session, the methods and procedure of pre-test and post-test measurements in this study were introduced by the researcher, so that the facilitator could have more understanding about the data collection process. Then, the facilitator practiced a telephone contact and a face-to-face interview with one family member of a patient with schizophrenia from the outpatient clinic, who consented to be the informant, and also rehearsed for seeking informed consent from the caregiver, and asking his/her health concerns. An evaluation of the performance was done immediately after the practice.

Post-workshop Practice and Supervision

After the workshop, practice of group facilitation and telephone interview had been arranged for the facilitator to an existing family group in order to ascertain and evaluate his learned skills of group facilitation and follow-up of families in-between group meetings. In addition, continuous supervision comprised consistent reviews of the audiotape of each session of the mutual support group in the pilot study by the researcher, one family therapist and the facilitator, and regular clarification of the problems and issues arisen in-between the group meetings.

APPENDIX 6 DESIGN, IMPLEMENTATION AND RESULTS OF PHASE 2 OF THE PILOT STUDY

1. DESIGN AND IMPLEMENTATION OF THE PILOT STUDY

An experimental pre-test and post-test control group design was used in this pilot study. A total of 48 families were selected randomly from the 185 families of the patients with schizophrenia from one regional psychiatric outpatient clinic in Hong Kong (i.e. the same as convenience sample of Phase 1 of the pilot study), and after they had completed the questionnaire, consisting of the families' and patients' outcome measures used in the Phase 1 of the pilot study, and in the main study. Then, they were allocated randomly to an experimental (mutual support) group (n= 24), or a control group (n= 24) receiving conventional family services. The primary outcome measure was family burden of care, using the Family Burden Interview Schedule (FBIS; Chien & Norman, 2004), and the secondary outcome measures included:

- family functioning using the Family Assessment Device (FAD; Sun & Cheung, 1997);
- family's perceived social support using the 6-item Social Support Questionnaire (SSQ6)- Level of satisfaction score (Chang, 1999);
- utilisation of family support services using the modified Family Support Services Index (FSSI; Chien & Norman, 2003); and
- patient's level of functioning using the Specific Level of Functioning (SLOF; Lee, 1999).

The detail information about the research instruments used in the study can be found in Section 5.3.4 of Chapter 5 ('Pilot Testing the Reliability and Validity of Outcome Measures'). Additional data not included in the questionnaire were collected from reporting of the subject caregivers every two weeks via telephone contact by the researcher and entered onto a data collection form. These data included: frequencies and severity of family conflicts in relation to patient care; frequencies of outdoor activities with family members, relatives or friends; and days of patient's re-hospitalisation.

Similar to the main study, inclusion criteria of the family carers were: (a) they lived with and cared for one relative with a primary diagnosis of schizophrenia and its subtypes according to criteria of the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (American Psychiatric Association, 1994); (b) their relative with schizophrenia suffered no co-morbidity of other mental illness during subject

recruitment and who had been diagnosed with schizophrenia for not > 5 years; (c) they were aged at least 18 and could understand and read Cantonese or Mandarin; and (d) they were free from any mental illness and agreed to participate voluntarily in the study. Families were excluded if they cared for more than one family member with mental illness, or they were the primary carers for less than three months.

1.1 Recruitment & randomisation

The eligibility of the convenience sample of 185 families to participate in this experimental study (Phase 2 of the pilot study) was checked, according to the set inclusion and exclusion criteria. When obtaining consent for this study, each patient and family had been already explained about the possibility and voluntariness of participation in this second phase, and the first phase of the pilot study. After the families had returned the questionnaire, they were asked by the researcher to draw a sealed opaque envelope, in which a number card indicating whether they were selected as the subjects of this part and which group they had been allocated to (1= experimental group, 2= control group and blank card and 3= not being selected). The envelopes were prepared by the researcher and stored in his office. The researcher was not aware of which group the family was allocated until the envelope was opened. The researcher and clinic staff were blind to the allocation. Nevertheless, the clinic staff were well-informed about the purpose and procedure of the trial and they would be asked for assistance in the process of group intervention such as checking the patient records and booking room and equipment for group meeting. The group list was only kept by the psychiatric nurse (group facilitator), inaccessible by the clinic staff. The researcher undertaking outcome measurements and qualitative interviews also did not have access to the group list.

1.2 Ethical considerations

Ethical approvals were obtained from the psychiatric outpatient clinic and the Clinical Research Ethical Committee, Faculty of Medicine at The Chinese University of Hong Kong (see Appendix 12). Data were collected over a period of seven months from the outpatient clinic for this experimental study (Phase 2 of the pilot study). As described in Chapter 5 (Section 5.3.3), 185 families consented to participate and completed the questionnaires for Phase 1 of the pilot investigation, with full explanation of the purpose of the study and their right as a research participant. A total

of 24 of them were randomly selected from the subject list and invited to participate in this clinical trial. They were also asked to consent to allow qualitative interview and group meetings to be audio-taped as if they were recruited to the treatment group in the trial. However, the subjects would be allowed to terminate participation in the trial when another group or family therapy was prescribed by attending psychiatrist during the intervention period as this was indicated as an urgent need and essential treatment for them. In this study, this situation did not occur.

1.3 Intervention and data collection procedure

Families (n= 24) randomised to the experimental group received the mutual support group programme, and at the same time, they received usual psychiatric outpatient services. They were asked not to inform the clinic staff and other families about their participation in the study and required to withhold from participation in any family therapy during the intervention period. Any queries were discussed with the group facilitator (the trained psychiatric nurse) of the study.

Families (n= 24) randomised to the control group received only the usual outpatient and family services provided by the clinic, such as the medical consultation and advice, social welfare and financial services provided by medical social worker, and counselling service by clinical psychologist if necessary. When the mutual support group programme had been revised in accordance with the findings of this pilot study, the control group subjects were asked to participate in the support group if they preferred.

Group attendance of each family carer was monitored continuously by the group facilitator. Through bi-weekly telephone contact, the facilitator could understand the situation of the families and motivate them to attend the group sessions. The preference of time and venue for meeting was carefully considered and any difficulties in attending group were discussed and resolved within the group. The families were also asked to report any other medical and psychological therapies participated during the group intervention, so that their effects would be taken into account in data analysis. Further arrangement of the continuation of the group and their follow-up was arranged with the clinic staff. The post-test measurement and the individual interview were done one week following the group intervention.

The researcher selected the pre-test questionnaire data and the socio-demographic data of the experimental and control groups from the survey findings of Phase 1. Post-test

measurement using the same questionnaire and additional data such as family conflicts and duration of re-hospitalisation were collected from the experimental and control group biweekly or monthly during the intervention. After completion of the post-test questionnaire, semi-structured interviews of 12 randomly selected treatment group subjects (50% of the treatment group) had been undertaken and tape-recorded by the researcher. An interview guide was designed to provide tentative agenda for the interview and it was also used in the main study. Open-ended questions were asked to facilitate the subjects to express their appraisals to group experience, for examples 'How do you feel about the participation in this support group?' and 'What are the effects/benefits to you and your family from the group meetings?' The researcher would probe responses and further elaborations in order to obtain rich data, such as 'Please tell me more about this idea' and 'Please explain any positive or negative impacts of this experience to you'. Every interview tape-record was reviewed carefully by the researcher immediately after it and if necessary, a second interview would be conducted for any point for clarification (Morse, 1997). During the treatment group meetings, the group facilitator was responsible to collect data of attendance and non-verbal behaviour within the mutual support group, and audio-taped the 12 group sessions. The duration of patients' re-hospitalisations was reported by the families and re-checked with outpatient records periodically.

1.4 Data analysis

Analysis of data was on intention-to-treat basis, which maintained the advantages of random allocation, and otherwise, might be lost if subjects were excluded from analysis when withdrawn or failure to comply (Bailer & Mosteller, 1992). Descriptive and inferential statistics were employed on the data on the pre-test and post-test measures and the demographic sheet using the SPSS for Windows version 11.0. The strategies for data analysis of this study are summarised in Table 1.

To test any difference in demographic characteristics between the experimental and control group, unpaired t-test (two-tailed) was used for demographic data in interval level, such as age and household income; Mann-Whitney U-test was used to test the difference in ranks of ordinal data of the two independent groups, such as mental condition and medication dosage in this study; and Chi-square test was used for nominal data, such as gender and relationship with the patient. As suggested by Polit and Hungler (1999), the distributions of mean scores of the two groups for comparison

were found to be normal and thus parametric t-tests were planned to compare the differences between the means.

Table 1 Pilot study strategies for analysis of pre- and post-test quantitative data

Purpose/hypothesis	Variables	Instrument/ method	Statistical tests
To describe families' and patients' characteristics in experimental and control group.	• Family carers' age, monthly household income, number of family members living with patient; • Patients' age and duration of mental illness (interval or ratio data)	Demographic data sheet	Means, standard deviations, ranges (minimum and maximum values)
	• Family carers' gender, education level, biological relationship with patient; • Patients' gender, present medication and mental condition in last 3 months (ordinal or nominal data)	Demographic data sheet	Frequencies and percentages
There is no statistical significant difference in demographic characteristics between the experimental and control group.	• Family carers' age, monthly household income, number of family members living with patient; Patients' age and duration of mental illness (interval or ratio data) • Families' and Patients' educational level; Patients' mental condition & medication dosage (ordinal data) • Families' and patients' gender; Relationship with patient (nominal data)	Demographic data sheet	• Unpaired t-test (two tailed) • Mann-Whitney U-test (if no. of subjects are not less than 20) • Chi-square test
There is no statistical significant difference on the primary outcome (FBIS) mean scores between the experimental and control group in response to treatments.	• Mean scores of FBIS in pre-test and post-test measures	FBIS within the questionnaire	• Paired t-test (two-tailed) for within group changes of mean scores; An analysis of co-variance (ANCOVA)
There is no statistical significant difference on mean scores of the secondary outcomes between the experimental and control group in response to treatments.	• Mean scores of FBIS, FAD, SSQ6, Family Support Services Index, and SLOF in pre and post-test	FBIS, FAD, SSQ6, Family Support Services Index, and SLOF within the questionnaire	• Paired t-test (two-tailed) for within group changes of mean scores; An analysis of co-variance (ANCOVA) test

There is no statistical significant difference on demographic variables and post-test mean scores of the primary and secondary outcomes between two experimental subgroups.	• Demographic variables of the experimental group • Post-test mean scores of the primary and secondary outcome measures	Demographic data sheet • Five scales in the questionnaire	• Unpaired t-test (two tailed), Mann-Whitney U-test or Chi-square test, according to the levels of measurement. • ANCOVA test
To compare the differences on the number of family conflicts and length of patient hospitalisation between the experimental and control group.	• Number of family conflicts and length of patient hospitalisation (in days) within three months	• Biweekly telephone interview by the group facilitator	• Unpaired t-test (two-tailed)

For analyses of the mean scores of the pre-test and post-test measures within and between the two groups, paired t-tests (two-tailed) were used for within group changes under two different occasions (i.e. pre and post-test), and on each continuous dependent variable (Gravetter & Wallnau, 2000). An analysis of covariance (ANCOVA) was used for between-group comparisons of the mean primary outcome scores in response to the treatments. The ANCOVA was selected because it avoids repeated testing of significance, thus reducing the risk of Type 1 error. It also allows the use of two or more carefully chosen covariates to reduce the error variance, such as the pre-test scores, and increase the chance of detecting a significant difference between groups (Stevens, 2002). For the secondary outcomes, ANCOVA was also used for the between-group comparisons. One way to control for the Type 1 error across multiple tests was to use a Bonferroni adjustment (Portney & Watkins, 2000). The level of significance for t-tests and ANCOVA tests was set at 0.01 (i.e. 0.05 divided by 5).

Comparisons of socio-demographic characteristics and post-test scores were undertaken between two subgroups of the experimental subjects. There were not significant statistical differences found between any characteristics of the two subgroups, using the similar parametric and non-parametric tests as above described for the comparisons between the experimental and control groups. Post-test scores of primary and secondary outcomes between the two subgroups were also compared using ANCOVA test, with pre-test scores as covariates. For the additional data such as

family conflicts and days of re-hospitalisations, unpaired t-tests (two-tailed) were used for between-group comparisons of their mean scores, and the level of significance was set at 0.05.

The interview data (12 interview scripts) and the support group meeting records (24 sessions for the two subgroups) were transcribed into Cantonese by the researcher and a few transcripts were checked with the psychiatric nurse (the group facilitator). Transcribed data were analysed by content analysis, as recommended by Morse and Field (1995). Interview scripts were used as starting point for coding and establishing themes. Transcribed group meetings were used to increase understanding of the group process and stages of development and confirm or refute the themes emerged from the interview data. Meaningful entities related to the understanding of the family appraisals of the group process, including mainly the feeling and attitude towards support group and fellow group members, perceived benefits and difficulties from group participation, and reasons for continuation or discontinuation of participation, and the development of support group and its influencing factors, were identified, coded and condensed to form categories and themes. To maintain objectivity and credibility in the interpretation of data, the researcher attempted to bracket his preconceived attitude and expectations regarding the support group, as suggested by Morse (1997), so that the reality described by the group participants could be interpreted accurately.

2. RESULTS OF PRE- AND POST-TEST MEASUREMENTS

2.1 Sample characteristics

The data from all of the 48 families participated in this study were used for final analysis. Three families in the experimental group were considered as discontinued treatment because they failed to attend 7 to 9 group meetings. Most of their cited reasons were: time constraint for shift duty of employment and household chores, a clash with other family activities, or not having trust relationship and open discussion with other group members. Average attendance of group sessions was 9.5, ranging from 3 to 12. However, no study participant was lost during intervention and at the post-test measurement.

Similar to the findings in Part 2, male (58.3% and 54.2%) was slightly more than female in the experimental and control groups. The largest age group was 30-49 years (75.0% for both groups); mean ages were 43.1 years (SD= 6.1) in the

experimental group and 45.2 years (SD= 5.1) in the control group. About two-thirds of them received education up to secondary school level (66.7 and 58.3%). They were mainly spouses (37.5% and 33.3%), children (29.2% and 25.0 %), and parents (25.0% and 29.2%) of the patients. Average monthly household income of the experimental group (HK dollars $16,500, SD= 1,580) was higher than the controls (HK dollars $12,300, SD= 2,050). There were no significant differences on these characteristics between the two groups at baseline measures, using Chi-square test (nominal), Mann-Whitney U-test (ordinal), or unpaired t-test (interval/ratio data).

Total number of male patients in the experimental and control groups (58.3% and 62.5%) was slightly more than female. About half of the patients ranged from 30 to 39 years (50.0% and 54.2%) and their mean ages were 39.9 years (SD= 5.0) and 38.3 years (SD= 6.5) in the experimental and control groups, respectively. Two-thirds of the patients (66.7%) in both groups had an education level of secondary school. Mental condition of about half of the patients (45.8%) in the two groups during the past three months was stable and more than one-third (37.5%) were worsened. In average, there were around two family members (M= 2.1, SD= 1.0) living with the patients in both groups. Medications taken by the patients in both groups were mainly conventional neuroleptics (87.9%). About half of them were in a medium dosage (54.2% and 50.0%) and one-third of them were in a low dosage (33.3% in both groups), in accordance with the American Psychiatric Association practice guideline (Bezchlibnyk-Butler & Jeffries, 1998). Duration of the patient illness at data collection was similar between the two groups, around two years. There were also no significant differences found between the two groups on all of these patient characteristics.

2.2 Comparisons of pre-test and post-test scores

The results of the comparisons of pre-test and post-test mean scores between experimental and control group are summarised in Table 2, with the means, standard deviations and 95% CI reported. T-tests were conducted to evaluate the within group changes in mean scores of the primary and secondary outcomes. There were statistically significant changes in the experimental group from pre-test to post-test in the following measures:

- A reduction of family burden (FBIS) scores (Paired-samples $t(23)= 2.80$, $p= 0.005$), whereas the control group had a slight decrease in burden score;
- A decrease in FAD scores (Paired-samples $t(23)= 2.45$, $p= 0.01$); and

- An increase in SSQ6- Satisfaction scores (Paired-samples t(23)= 2.97, p= 0.008).

With the subjects' scores on the pre-test as covariate, ANCOVA test was conducted to compare the post-test scores between experimental and control group. Preliminary checks were conducted to ensure no violations of the assumptions of normality, linearity, homogeneity of variances, homogeneity of regression slopes, and reliable measurement of the covariate (Tabachnick & Fidell, 2001). After adjusting for the pre-test scores, there were significant differences between the two groups on the post-test scores of the FBIS, F(1,45)= 4.95, p= 0.003 and eta squared= 0.68, and the SSQ6- Satisfaction score, F(1,45)= 5.11, p= 0.002 and eta squared= 0.70. The eta squared statistics (0.68 and 0.70) indicated large effect sizes (Cohen, 1992). Mean scores of the other three outcome measures including FAD, FSSI and SLOF, did not show significant differences between groups (p> 0.01). With three selected socio-demographic variables (i.e. monthly income, duration of illness and mental condition) entered as the covariates, there were no significant relationships found between these covariates and the post-test scores of the FBIS and SSQ6, as indicated by an eta squared value of each from 0.10 to 0.14 (p> 0.05).

Post-test scores of the FBIS, FAD and SSQ6 – level of satisfaction scores between the two subgroups (n= 12) of the experimental subjects were compared, using ANCOVA test and their pre-test scores as covariates. There were no significant differences between two subgroups on three measures (i.e. p> 0.05).

Frequencies of family conflicts during intervention ranged from 20 to 45 (Mean= 25.6, SD= 3.1, 95% CI= 23.7 - 26.6) in the experimental group and from 24-50 (Mean= 28.1, SD= 6.9, 95% CI= 26.7 - 30.2) in the control group. Length of re-hospitalisations for the patients ranged from 0 to 21 days ((Mean= 10.8, SD= 5.1, 95% CI= 9.3 - 12.3) and from 0 to 28 days (Mean= 13.8, SD= 6.4, 95% CI= 11.1 - 15.4) in the experimental and control groups, respectively. Results of unpaired t-test (two tailed) for these scores between groups were non-significant (p> 0.10).

3. RESULTS AND DISCUSSION OF PROCESS EVALUATION: INTERVIEWS AND GROUP SESSIONS

The findings from the interview and group session data related to the phases of group development and the process evaluation of the group intervention indicate some important factors influencing positive, desirable changes of personal involvement and commitment to group and group integrity, and cohesiveness throughout the group

Table 2 Comparisons of pre-test and post-test scores between the experimental and control groups (N=48) in pilot study

Instrument	Experimental (n = 24)							Control (n = 24)									
	Pre-test			Post-test			Paired t-test	Pre-test			Post-test			Paired t-test	ANCOVA F(1, 45)*	P	Eta square
	M	SD	95% CI	M	SD	95% CI		M	SD	95% CI	M	SD	95% CI				
FBIS	29.3	5.0	28.2-30.6	24.3	4.6	23.3-25.2	-2.80, p=0.005	29.7	4.9	28.8-30.9	27.5	4.9	26.0-28.8	-1.74, p=0.10	4.95	0.003	0.68
FAD	20.1	4.8	19.8-20.4	16.9	4.1	16.5-17.4	2.85, p=0.01	19.3	3.5	18.9-19.7	18.4	4.3	17.9-18.9	2.00, p=0.06	2.14	0.06	0.45
SSQ6 – Satisfaction score	2.2	0.5	2.1- 2.3	2.5	0.5	2.4- 2.5	2.97, p=0.008	2.1	0.5	2.1- 2.2	2.2	0.4	2.2- 2.3	1.89, p=0.08	5.11	0.002	0.70
FSSI- in need	3.8	0.5	3.8- 3.9	3.9	0.5	3.8- 3.9	1.32, p=0.2	3.9	0.6	3.8- 3.9	3.9	0.4	3.8- 3.9	-1.31, p=0.20	1.03	0.2	0.28
SLOF	105.3	19.8	102.1-109.2	112.8	20.3	109.1-115.6	2.01, p=0.06	107.2	20.1	104.1-111.2	109.1	13.4	105.1-113.8	1.11, p=0.25	2.82	0.03	0.50

Note: * F value of one-way between-groups analysis of covariance (ANCOVA) was indicated, with the subjects' scores on the pre-test as the covariate in this analysis.

FBIS: Family Burden Interview Schedule; FAD: Family Assessment Device; SSQ6: Six-item Social Support Questionnaire; FSSI: Family Support Service Index; SLOF: Specific Level of Functioning.

development. These factors were considered and reviewed by the facilitator and the researcher for optimising the effect of a mutual support group in the main study. They are summarised and discussed as follows:

Perceived progression through phases of the group

The data from the interviews and taped group sessions with family carers showed that the five phases of group development (engaging, recognition of psychological needs, dealing with psychosocial needs of self and family, adopting new roles and challenges, and preparation for ending of the group and their future) had been achieved by most group participants. Five of the 12 participants (interviewees) indicated some difficulties in getting through the first group phase (engaging), in particular building trust relationship with other members, understanding and accepting their roles and responsibilities in reciprocal learning and support, and open discussion of their life situation and personal feelings in relation to caring for the patient with mental illness and its effects to family. An example of their difficulties and ambiguous feelings is revealed by the verbatim quotation from a taped group session given below:

> "I think it is better for me to put down my mistrust and suspicions to all of you. But I am not comfortable to be so open in discussion, because I had been stigmatised, isolated and ignored by others and thus I had withdrawn from any social activities with most relatives and friends. I have seldom talked about my family situation with other people, because I was afraid of this being the laughing-stock of others." (Caregiver C, end of 1st group session)

One of the family caregivers failed in working through the first group phase, and quitted from the group after the third session. During interview, she stated,

> "I could not share my feeling with anybody in the group because they seem not concerning about my questions and requests. I felt regret that I had to quit from the group." (Caregiver J, interview 17, paragraph 48)

The second phase of the group was not easy to get through, but most of the families satisfied with the gradual changes during this phase. However, psychological tension of the participants was indicated from the interview and group session data in their resolution around power, control and decision-making issues within the group. As one family carer said during the fourth session:

> "It is really difficult for me to follow others' instructions and orders, because I usually made decisions for other family members at home. Also, the group members sometimes seemed very unreasonable and authoritative in making decisions about the topics of discussion and not always having adequate time for me to share about my concerns." (Caregiver H, within 4th group session)

However, she indicated in the later sessions that:

"I understand that it is very important for each of us to have mutual respect, sharing of information and concerns, and even rooms for expressions of intense emotions and feelings about patient care. If we only focused on concerns and problems of ourselves, we could not listen to others and learn the alternative ways of solving problems from others' experiences. I now feel much appreciated that the other group members could be so patient to me, withstand my self-centredness and unreasonable demands on them and listen to what I said." (Caregiver G, within 8th group session)

After the second phase, the support group appeared to be run smoothly and have a good progress. Many group members indicated during the interview that they got more understanding about the patient illness and the related illness behaviour and they could recall different ways to deal with their negative emotions to patient and find them effective. In many occasions, they could experience effective communications and improved relationship with patient and relatives. This could be reflected from their pleasant smiles and reporting of some positive and joyful interactions and activities with patient after a few group sessions. They also reported that they could establish their specific home management strategies, for examples, more effective finance and budgeting and maintenance of tidy and hygienic home environment.

However, their new learning from group members, such as coping skills of stressors related to caregiving and doing some positive things with the patient (such as accompanying the patient to follow-up in the clinic), use of problem-solving approach in management of patient's problems and demands, and minimising conflicts and distress within family, required more behaviour rehearsals and practice in their 'real' family life. Therefore, more time should be considered for discussion and practice of the new roles and challenges in caregiving (the fourth group phase), as suggested by most of the participants in the pilot study. At last, a few family carers indicated that there was not sufficient time to discuss continuation of the support group, their future and the related issues such as separation anxiety and the importance of independent living and use of problem-solving skills. One extra session could be conducted for those who were interested in the group continuation and their future planning to discuss for detail arrangements.

Thematic analysis of the group process

From the interview data and taped group sessions, categories that might influence the development and success of the family support group were identified. These categories related to three independent themes: individual changes, positive and

negative group characteristics and influences of external environment, are discussed accordingly, and these themes and categories are summarised in Table 3.

Table 3 Themes and categories derived from interviews of family carers and taped group sessions in pilot study

Themes	**Categories**
1. Positive individual changes	a) Changes in personal identity and perception of mental illness b) Adoption of new coping methods and skills for caregiving
2. Positive and negative group characteristics	a) Group ideology and consensus b) Social climate - Task orientation - Feeling of empowerment c) Inhibitory factor influencing group development - Irregular or low group attendance
3. Influences of external environment	a) Perception of professional involvement and support b) Support from family members and close relatives outside group

Theme 1 – Positive individual (personal) changes within the support group consisted of two categories: (a) changes in personal identity and perception of mental illness and (b) adoption of new coping methods and skills for caregiving. The family members of patients with schizophrenia, like the ones in this study, experienced feelings of loss and uncertainty and were confronted with emotions of shame, guilt and anger, because they thought they are required to be responsible to the mental illness within their family (Barrowclough & Tarrier, 1992). Like their patients, they felt "stigmatised and socially isolated with relatives and friends" (Caregiver G, within 5th group session). They emphasised that the major contribution of the mutual support group to them with deviant labels was to facilitate them to "reconstruct a new positive identity" (Caregiver A, within 6th group session). The families in the support group at first identified themselves with group members through the sense that they were going through a similar stressful and negative experience of caregiving – they often referred themselves to be 'all in the same boat'. In time, they recognised that they could achieve "what the others had attained in caring for their family and patient" (Caregiver J, interview no, 15, paragraph 22). As one caregiver said, "we are more positive about self-identity, and also we begin to recognize our importance and responsibility in caring for the patient" (Caregiver D, end of 4th group session).

It was important that the families, who had little knowledge about mental illness and diminished selves due to their misunderstanding and distress on caregiving prior to group participation, had changed progressively to making sense of the illness reality and plausible explanations for their responsibilities and difficulties in caring for their patient. These changes were consistent with the purpose of existence of family support groups, which are attachments among group members facing the similar life problems that serve to improve adaptive competence in dealing with short-term crises and life transition as well as long-term challenges, stresses and privations (Gottlieb, 1988; Medvene & Krauss, 1989). These changes could also be related to the dialectical process of the group, that is, group members could have chances to think about the different ideas and different ways of doing things among the members, and discuss their pros and cons (Smith, 1991).

The families in the support group had their different ways of identity transformation in accordance with their re-construction of ways of coping and psychological well-being. Some of them had obtained insight of a meaningful life (of their own), even they would live with unresolved difficulties; this re-definition of their life meaning was suggested to be gained through the group membership and repeated practice of being learned from other group members. An example of a verbatim quotation from an interview indicates one of these insights:

> "Life had been the pits for me that months. I was feeling lonely and guilty, since my family recognized that one of our beloved family members became 'mad'. My friends invited me to outings and parties, I did not want to go and meet with them… However, after joining this group, I think I have to rebuild a more 'normal' and healthy life and reach out to others. I can't just stay with my beloved son and let myself become socially isolated, powerless and helpless. I must do something to improve my life." (Caregiver E, interview 11, paragraph 56)

From reframing of their life problems and sharing openly how they managed their patient, most of the families showed a change in perception of the illness, thus, a relief from victim blaming, and began to act compassionately toward the sick relative.

There was another positive perception of the patient's illness with more internal control and acceptance of the patient, as identified from some of the families. Nearly one-half of the families indicated learning a good sense of internal control of their situation, for example in the fifth group session, one carer said,

> "We cannot control what is in their outside environment, including patient embarrassing and annoying behaviour and others' emotional reactions, but we can manage what is inside

us and our emotions and temper. I really understand that all these troubles are not the patient's fault or what the person intend to do." (Caregiver F, within 5th group session)

However, another half of them still sometimes found annoying about the patient's behaviour and could not fully accepted open discussions among the members about their adverse family situations. They admitted that they "need more time to adopt an open personal disclosure within the group" (5th group session, Caregiver C). A few remained focusing on finding a causal interpretation of the patient's illness despite having more understanding about the illness. A mother carer who irregularly attended the group, illustrated this maladaptive way of disease definition:

"My feelings of caregiving are still guilty and uncertain, so my group participation could not take these feelings away. I am assumed to continue caring for my young son, and feel I might have done something to cause this. In this support group, I only learned a little about the illness." (Caregiver H, interview 18, paragraph 48).

This appeared to suggest for more discussion and learning about the illness and its effects to family, and therefore the researcher considered increase sharing this information during group sessions in the main study.

The final category under the theme of individual changes of thee family carers in the support group is the development of more effective coping methods through members' sharing of their personal data and past experience about caregiving. As a result of imparting information and disclosing different perspectives of caring for their relative with schizophrenia among the group members, including factual, psychological or personal ones, the family caregivers gained at least some experiential knowledge from others who lived through and resolved their life problems, and these would not be obtained from the expertise of health professionals. For example, one carer said, "After joining the group, I have experienced improved communication with patient, more positive view of patient illness, relief from shame, and an increasing power and confidence to help self and others" (Caregiver C, interview 3, paragraph 14). For developing new coping methods, the group participants indicated different ways of effective coping skills. For example, one carer told the group during the sixth session and restated in the interview:

"I have learned to soften my tone of voice and avoid arguing with my husband (patient) when I saw him suddenly shouting and talking to the air. I could not stay calm in the past. But I now understand why he got such behaviour, and also I feel empathy that he suffered a lot from this and all other symptoms." (Caregiver E, 6th group session)

However, within this period of group intervention, it was sometimes difficult to some families in discussing the 'taboo area' of their family life, in particular when they

only met a few sessions at the early group stage. These shared secrets are the basis for the formation of the support group and enhancing their cohesiveness. It is believed that many of these personal but important issues can be ventilated within a group of similar people who do understand and, beyond that, can help one another regain self-respect and esteem (Wilson, 1995).

Theme 2 – positive or negative characteristics in the support group, were identified by the family caregivers to be important for optimal effects on their group participation and obtaining mutual benefits in the group. The first positive characteristic mentioned by the group members was the early establishment of group ideology and consensus. As indicated in the first and second group sessions, the family caregivers had discussed thoroughly the group's explicit beliefs about the group, their common goals and objectives, the rules of behaviour, and the ways of expression of ideas within these two meetings. The facilitator guided the group to talk about everyone's ideas and suggestions, and all of them emphasised that they would take seriously about the agreed rules and goals. For examples, many caregivers indicated a strong and explicit group belief during the first meeting that: "we should remind ourselves our common goal of promoting mutual help and support among us in order to live more happily and harmoniously with our family" (Caregiver D, 1st group session) and "everyone should absorb group ideas, not just staying in their own way, and as a living reality that is to face with daily challenges and learn how to live with some unresolved problems" (Caregiver F, end of 1st group session). It appeared that most of the families agreed with this saying and asked the facilitator to remind them when they did not show this mutual support behaviour.

From the interview data, a few family carers did express positive effect from the simple agreed ideology of the group in their replies, for an example:

> "Our group members cared for each other wholeheartedly as we proposed in the first meeting. I really experienced a release from the horror of the distressing event, as mentioned by the other families or friends in the group, and the crushing blow of my loss in caring for my daughter (patient). I learned to not only centre in their own pain, but reach out to others in empathic ways." (Caregiver B, interview 19, paragraph 28)

The second positive group characteristic was the social climate perceived by members, mainly including task orientation. Task orientation concerns the emphasis on practical problem solving and learning specific skills from the group (Moos, Finney & Maude-Griffon, 1993). This support group had been commented by most of the families to be mainly orderly and problem focused one. They found that some methods of

patient management suggested by the group members were effective in practical use. This was reflected from the verbatim quotations from two caregivers:

> "I feel our group was well-structured, systematic with themes in each session, and was good to have much opportunities to discuss about our real problems. I could learn how to manage my relative with the mental illness. I can remember a variety of methods had been suggested by the group-mates to improve my relative's drug compliance. I had never thought about these before, and some of them were effective in my practical use." (Caregiver D, interview 12, paragraph 20)

It was also interesting to note that the caregivers experiencing more stressful events in caregiving and greater resultant distress were more likely to attend the support group (i.e. with regular attendance) and ask for help actively from the members and the facilitator. As a few caregivers in this group admitted to be very stressful in providing care for their patient, they were found to engage actively and be committed highly to the group activities and discussion. They said to the facilitator,

> "I felt much relieved from stress immediately after each group session and I could go back home and interact with my relative with mental illness more effectively." (Caregiver E, end of 8th group session).
> "In every session, I could take some tips of handling the patient back into my everyday life and I felt being accepted by others even not any or little success with using these suggestions." (Caregiver J, at the end of the 9th group session).

However, this internal affiliation between group members appeared to develop gradually and still going on at the end of the intervention. This affiliation and the reciprocal 'give-and-take' relationships were further explored during the group participation in the main study.

However, most of the group members indicated that intense anger and negative emotions sometimes were not being accepted. They might not know how to deal with these emotions and the facilitator had to call a time break to settle these strong emotions. There were also some disagreements and conflicts within the group, which could not be easily settled by the group members themselves. They admitted that the facilitator did help them to reduce the aggression among the members, but the unresolved arguments and conflicts might cause some members to feel negative and disappointed to the group participation, as indicated by three interviewees. And, they stated that they were in lack of techniques and time to resolve these conflicts. Methods and skills of conflict management would be discussed between the researcher and the facilitator before conducting the group intervention in the main study.

The second positive characteristic of the support group was the feeling of empowerment. Importantly, the group members could obtain some experiential knowledge by the group members. The essence of empowerment, which is to enable the families to help themselves (Gidron & Chesler, 1995), might occur when the caregivers received more knowledge about caring for the patient and practiced the learned skills from other group members effectively in family life. In consistent with explanation by Wong and Chan (1994), some family carers reported gaining a lot in the ability to reach out to others, to tackle problems of patient care step by step, to manage feelings of frustrations and denials, and to be more positively face with the life difficulties. However, this feeling of empowerment had not yet been firmly developed in most of the carers. This was illustrated by what one caregiver said,

> "I feel my group members really supporting me to change my life. It is important for me to start practising the skills of caring learned form them and doing something for my family. I have to put more efforts to change my negative feelings to my son (patient) and support him to face with the illness. I feel more confident to achieve this from now on." (Caregiver E, 10th group session)

This feeling of empowerment seems to be strengthened when one becomes able to take action for oneself and on behalf of others with self-confidence and empathy (Kurtz, 1997). But its development took time and required adequate and appropriate support from other group members. However, this feeling should be reinforced in participation in the support group in the main study.

The final category identified within the second theme was the one inhibitory factor in the group development. The inhibitory factor identified was an irregular or low attendance by the group members. It has been commonly but inappropriately accepted to have instable attendance in a social or therapeutic group (Meissen & Volk, 1995). This excuse often caused a lot of difficulties to work out an effective therapeutic group as one in this study. The support group in the study had high attendance in average and was not open membership in nature. However, some difficulties were encountered and raised by the caregivers who had lower group attendance, mainly included the inhibitory or negative effects on "building a more trusting relationship between members" (Caregiver B, interview 2, paragraph 13), "an open and intimate social climate" (Caregiver H, interview 8, paragraphs 20), and "more positive behavioural changes and effective coping skills for caregiving" (Caregiver D, interview 4, paragraph 25). Therefore, more attention would be made in encouraging regular attendance of group members, in particular more flexibility in time of group meetings

and regular contacts and encouragement of group participation, not only from the facilitator but also from some enthusiastic group members (Luke et al., 1993).

Theme 3 – influences of the external environment was the last theme identified from the qualitative data. First, perception of professional involvement and support was one category, which was mainly indicated from the interview data. Although the support group had been run separately from the formal health care services, the group members thought that their group would be desirable to have more interactions with health professionals, and thus they could seek professional help and support individually, if necessary. The facilitator was identified as the appropriate resource person to refer any services or assistance from the health care system. As other mutual support groups, relationships and linkages with health professionals were seen primarily in terms of individual members separately in need of professional support (Stewart, 1990). Availability of these linkages in different levels were indicated by majority of the caregivers as "important to our individual needs, such as psychological and medical consultations, and additional support for patient care, such as day hospital service for day care and training of patients by the outpatient clinic and telephone consultation and home visits by community psychiatric nurses" (Caregiver C, 5th group session). This finding was in consistent with the results of the pre and post-test measurements in Phase 1, that the families in the support group received more family services in need during post-test as compared with their pre-test scores using Family Support Services Index. However, the most preferred level of involvement and way of partnership with health professionals have not been examined in details.

Another category within this theme was the support available from family members and close relatives outside the group. This support was seen as equally important as the support obtained from the health professionals. In consistent with the findings of studies on family support in caring for a relative with mental illness (Toseland & Rossiter, 1989; Barrowclough et al., 1998), family members of the carers were seen as immediate physical and emotional supports during their patient care provision and their practice of learned skills from the group. The importance of social support from other family members could be illustrated by what one carer said:

> "It is real important to have someone present and support my actions and care provision to my daughter (patient) at home. My family members could listen to my little success in working out the things learned from the group and also the difficulties the family as a whole had to face with. They could understand what I was doing, and I

think, no other people can provide such immediate support to me in the family." (Caregiver A, within 6th group session).

For the support of other people in their social network, it appeared to vary according to the number of people available to the carers and their relationship with them. In general, from the interview data, the more the number of friends and peers available and the closer their relationship with the carers, the better and more satisfactory the social support that the caregivers perceived to have. The relationship between the carers and other people in their social network outside the group would be explored in the main study, in order to better understand their perceptions of social support outside group and its influence to the effectiveness of the support group.

4. CONCLUSION

In summary, the feasibility of the method and process of mutual support group intervention and the facilitator training workshop was examined in Phase 2 of the pilot study and a trial run of the family support group was conducted with positive results. The mutual support group programme was found to have effects on the primary and some secondary outcomes. These included a significant reduction in family burden of care, and increased family functioning and satisfaction with social support. However, the effects of the support group intervention on the patients although positive, were non-significant between the experimental and control group with respect to improvements in their specific level of functioning and length of hospital stay. These findings warrant further investigation of the effectiveness of mutual support group intervention for the family carers with a larger sample size of patients and their families in the main study. They also alerted the researcher to amendments required in the design of the main study.

In addition the pilot study identified some preliminary themes and factors influencing the therapeutic process and possibly the effectiveness of a mutual support group intervention for the family carers, through content analysis of the transcripts of the group meeting and semi-structured interview data. These themes and categories provide a valuable basis for development in hypotheses about which aspects or ingredients of the group intervention will have most effects on families, and thus should be investigated further in the main study.

APPENDIX 7 FIVE PSYCHOSOCIAL MEASURES

APPENDIX 7 – 1: FAMILY BURDEN INTERVIEW SCHEDULE

Date of Assessment: _____ Client Number: _____

Please enter the rating of each item in the space provided and comment on items with special consideration.

Key: 0 = No burden, 1 = Moderate burden, 2 = Severe burden.

	Level of burden (0-2)	**Remarks**
I. Financial Burden		
1. Loss of patient's income	( )	_____
2. Loss of income of other family members	( )	_____
3. Need to work after retirement	( )	_____
4. Expenses of patient's illness	( )	_____
5. Expenses due to other necessary changes in arrangement	( )	_____
6. Loans taken	( )	_____
7. Debts of patient	( )	_____
8. Any other planned activity needing finance postponed	( )	_____
II. Effect on Family Routine		
1. Patient not attending work, school, etc.	( )	_____
2. Patient unable to help in household duties	( )	_____
3. Disruption of activities due to patient's illness and care	( )	_____
4. Other family members missing school, meal, etc.	( )	_____
III. Effect on Family Leisure		
1. Stopping of normal recreational activities	( )	_____
2. Absorption of another member's holiday and leisure time	( )	_____
3. Lack of participation by patient in leisure activity	( )	_____
4. Planned leisure activity abandoned	( )	_____

IV. Effect on Family Interaction

1. Ill effect on general family atmosphere ( ) _____
2. Other members arguing over the patient ( ) _____
3. Reduction or cessation of interaction with friends and neighbours ( ) _____
4. Family becoming secluded or withdrawn ( ) _____
5. Any other effect on family or neighbourhood relationships ( ) _____

V. Effect on Physical Health of Other family Members

1. Physical illness in any family member ( ) _____
2. Any other adverse effect on others ( ) _____

VI. Effect on Mental Health of Other Family Members

1. Any member seeking professional help for psychological illness ( ) _____
2. Any member becoming depressed, weepy, irritable ( ) _____

VII. Burden on family as a whole ( ) _____

_____

Total score: _____

APPENDIX 7 – 2: FAMILY ASSESSMENT DEVICE

Part A: Family Functioning

From the following statements, Please circle the number, which most accurately reflects your existing family situation.

1____2____3____4
4 - Strongly disagree
3 - Disagree
2 - Agree
1 - Strongly agree

1.	Planning family activities is difficult because we misunderstand each other.	1____2____3____4
2.	We resolve most everyday problems around the house.	1____2____3____4
3.	When someone is upset the others know why.	1____2____3____4
4.	When you ask someone to do something, you have to check that they did it.	1____2____3____4
5.	If someone is in trouble, the others become too involved.	1____2____3____4
6.	In times of crisis we can turn to each other for support.	1____2____3____4
7.	We don't know what to do when an emergency comes up.	1____2____3____4
8.	We sometimes run out of things that we need	1____2____3____4
9.	We are reluctant to show our affection for each other.	1____2____3____4
10.	We make sure members meet their family responsibilities.	1____2____3____4
11.	We cannot talk to each other about sadness we feel.	1____2____3____4
12.	We usually act on our decisions regarding problems.	1____2____3____4

4 - Strongly disagree
3 - Disagree
2 - Agree
1 - Strongly agree

13. You only get the interest of others when something is important to them. 1___2___3___4
14. You can't tell how a person is feeling from what they are saying. 1___2___3___4
15. Family tasks don't get spread around enough. 1___2___3___4
16. Individuals are accepted for what they are. 1___2___3___4
17. You can easily get away with breaking the rules. 1___2___3___4
18. People come right out and say things instead of hinting at them. 1___2___3___4
19. Some of us just don't respond emotionally. 1___2___3___4
20. We know what to do in an emergency. 1___2___3___4
21. We avoid discussing our fears and concerns. 1___2___3___4
22. It is difficult to talk to each other about tender feelings. 1___2___3___4
23. We have trouble meeting our bills. 1___2___3___4
24. After our family tries to solve a problem, we usually discuss whether it worked or not. 1___2___3___4
25. We are too self-centered. 1___2___3___4
26. We can express feelings to each other. 1___2___3___4
27. We have no clear expectations about toilet habits. 1___2___3___4
28. We do not show our love for each other. 1___2___3___4
29. We talk to people directly rather than through go-betweens. 1___2___3___4
30. Each of us has particular duties and responsibilities. 1___2___3___4
31. There are lots of bad feelings in the family. 1___2___3___4
32. We have rules about hitting people. 1___2___3___4
33. We get involved with each other only when something interests us. 1___2___3___4
34. There's little time to explore personal interests. 1___2___3___4
35. We often don't say what we mean. 1___2___3___4
36. We feel accepted for what we are. 1___2___3___4

4 - Strongly disagree
3 - Disagree
2 - Agree
1 - Strongly agree

37.	We show interest in each other when we can get something out of it personally.	1____2____3____4
38.	We resolve most emotional upsets that come up.	1____2____3____4
39.	Tenderness takes second place to other things in our family.	1____2____3____4
40.	We discuss who is to do household jobs.	1____2____3____4
41.	Making decisions is a problem for our family,	1____2____3____4
42.	Our family shows interest in each other only when they can get something out of it.	1____2____3____4
43.	We are frank with each other.	1____2____3____4
44.	We don't hold to any rules or standards.	1____2____3____4
45.	If people are asked to do something, they need reminding.	1____2____3____4
46.	We are able to make decisions about how to solve problems.	1____2____3____4
47.	If the rules are broken, we don't know what to expect.	1____2____3____4
48.	Anything goes in our family.	1____2____3____4
49.	We express tenderness.	1____2____3____4
50.	We confront problems involving feelings.	1____2____3____4
51.	We don't get along well together.	1____2____3____4
52.	We don't talk to each other when we are angry.	1____2____3____4
53.	We are generally dissatisfied with the family duties assigned to us.	1____2____3____4
54.	Even though we mean well, we intrude too much into each other's lives.	1____2____3____4
55.	There are rules about dangerous situations.	1____2____3____4
56.	We confide in each other.	1____2____3____4
57.	We cry openly.	1____2____3____4
58.	We don't have reasonable transport.	1____2____3____4
59.	When we don't like what someone has done, we tell them.	1____2____3____4
60.	We try to think of different ways to solve problems.	1____2____3____4

Thank you!

APPENDIX 7 – 3: SHORT FORM SOCIAL SUPPORT QUESTIONNAIRE (SSQ6)

Instructions

The following questions ask about people (family/friends) in your environment who provide you with help or support. Each question has two parts.

For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the person's initials and their relationship to you (see the example). Do not list more than 1 person for each of the numbers beneath the question. Do not list more than nine persons per question.

For the second part, circle how satisfied you are with the overall support you have.

If the best answer for a particular question is no one, put a tick in the bracket next to "No one", but still rate your level of satisfaction.

Please answer all questions as best you can. All your responses will be kept confidential.

Example : Who can you count on to console you when you are very upset ?

No one( )	2) L.M. (friend)	4) T.N (father)	6)	8)
1) T.N. (brother)	3) R.S. (friend)	5)	7)	9)

How satisfied overall ?

6- very satisfied	5- fairly satisfied	4- a little satisfied	3- a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

---

Section II

1. Who can you count on to distract you from your worries when you feel under stress ?

No one ( )	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

How satisfied overall ?

6- very satisfied	5- fairly satisfied	4- a little satisfied	3- a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

---

2. Who can you really count on to help you feel more relaxed when you are under pressure or tense?

No one ( )	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

How satisfied overall ?

6- very satisfied	5- fairly satisfied	4- a little satisfied	3- a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

3. Who accepts you totally, including both your worst and your best points ?

No one ( ) 1) 4) 7)
2) 5) 8)
3) 6) 9)

How satisfied overall ?

6- very satisfied | 5- fairly satisfied | 4- a little satisfied | 3- a little dissatisfied | 2- fairly dissatisfied | 1- very dissatisfied

---

4. Who can you really count on to care about you, regardless of what is happening to you ?

No one ( ) 1) 4) 7)
2) 5) 8)
3) 6) 9)

How satisfied overall ?

6- very satisfied | 5- fairly satisfied | 4- a little satisfied | 3- a little dissatisfied | 2- fairly dissatisfied | 1- very dissatisfied

---

5. Who can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

No one ( ) 1) 4) 7)
2) 5) 8)
3) 6) 9)

How satisfied overall ?

6- very satisfied | 5- fairly satisfied | 4- a little satisfied | 3- a little dissatisfied | 2- fairly dissatisfied | 1- very dissatisfied

---

6. Who can you count on to console you when you are very upset ?

No one ( ) 1) 4) 7)
2) 5) 8)
3) 6) 9)

How satisfied overall ?

6- very satisfied | 5- fairly satisfied | 4- a little satisfied | 3- a little dissatisfied | 2- fairly dissatisfied | 1- very dissatisfied

---

Thanking you for your help in completing this questionnaire.

APPENDIX 7– 4: MODIFIED FAMILY SUPPORT SERVICES INDEX (BILINGUAL VERSION)

Please indicate the health services you require (in the first column) and you are receiving (in the second column):

		Needing 需要 Yes	Needing 需要 No	Receiving 得到 Yes	Receiving 得到 No
1. Day Programming	病者日間服務	☐	☐	☐	☐
2. Transportation	交通工具	☐	☐	☐	☐
3. Recreational Activities	康樂活動	☐	☐	☐	☐
4. Case Management	個案護理	☐	☐	☐	☐
5. Specialized Therapies	特別治療	☐	☐	☐	☐
	(例如鬆弛治療、心理治療等)				
6. Residential Program Information	住宿服務資料	☐	☐	☐	☐
7. Financial Planning *Information*	家庭財務計劃資料	☐	☐	☐	☐
8. Support Group	支持小組	☐	☐	☐	☐
9. Family Counselling	家庭輔導	☐	☐	☐	☐
10. Patient Counselling	病者輔導	☐	☐	☐	☐
11. Government Benefits	政府福利	☐	☐	☐	☐
12. Parenting Skills	照顧病者技巧	☐	☐	☐	☐
13. Home Care	家居護理服務	☐	☐	☐	☐
14. In-Home Nursing	社康護理服務	☐	☐	☐	☐
15. Special Equipment	特別用具	☐	☐	☐	☐
	(例如輪椅、枴杖等)				
16. Information Hotline	資詢熱線	☐	☐	☐	☐

APPENDIX 7 – 5: SPECIFIC LEVEL OF FUNCTIONING SCALE

Instructions:
Circle the number that best describes this person's *typical* level of functioning on each item listed below. Be as accurate as you can. If you are not sure about a certain rating, ask someone who may know or consult the case record. Mark only one number for each item. Be sure to mark all items. Please sum up all the subscales.

Client No.: _____ Date of assessment: _____

SELF-MAINTENANCE

A. Physical Functioning	*No problem*	*Problem, but no effect on general functioning*	*Slight effect on general functioning*	*Restricts general functioning substantially*	*Prevents general functioning*	
1. Vision	5	4	3	2	1	
2. Hearing	5	4	3	2	1	**Total Scale A**
3. Speech impairment	5	4	3	2	1	
4. Walking, use of legs	5	4	3	2	1	
5. Use of hands and arms	5	4	3	2	1	
B. Personal Care Skills	*Totally self-sufficient*	*Needs verbal advice or guidance*	*Needs some physical help or assistance*	*Needs substantially help*	*Totally dependent*	
6. Toileting (use toilet properly; keeps self and area clean)	5	4	3	2	1	
7. Eating (use utensils properly; eating habits)	5	4	3	2	1	
8. Personal hygiene (body and teeth; general cleanliness)	5	4	3	2	1	
9. Dressing self (dresses self, selects appropriate garments)	5	4	3	2	1	
10. Grooming (hair, make-up, general appearance)	5	4	3	2	1	**Total Scale B**
11. Care of own possessions	5	4	3	2	1	
12. Care of own living space	5	4	3	2	1	

SOCIAL FUNCTIONING

C. Interpersonal Relationships	*Highly typical of this person*	*Generally typical of this person*	*Somewhat typical of this person*	*Generally untypical of this person*	*Highly untypical of this person*	
13. Accepts contact with others (does not withdraw or turn away)	5	4	3	2	1	
14. Initiates contact with others	5	4	3	2	1	
15. Communicates effectively (speech and gestures are understandable and to the point)	5	4	3	2	1	
16. Engages in activities without prompting	5	4	3	2	1	
17. Participates in groups	5	4	3	2	1	**Total Scale C**
18. Forms and maintains friendships	5	4	3	2	1	
19. Asks for help when needed	5	4	3	2	1	
D. Social Acceptability	*Never*	*Rarely*	*Sometimes*	*Frequently*	*Always*	
20. Verbally abuses others	5	4	3	2	1	
21. Physically abuses others	5	4	3	2	1	
22. Destroys property	5	4	3	2	1	
23. Physically abuses self	5	4	3	2	1	
24. Is fearful, crying, clinging	5	4	3	2	1	
25. Takes property from others without permission	5	4	3	2	1	**Total Scale D**
26. Performs repetitive behaviours (pacing, rocking, making noise)	5	4	3	2	1	

COMMUNITY LIVING SKILLS

E. Activities	*Totally self-sufficient*	*Needs verbal advice or guidance*	*Needs some physical help or assistance*	*Needs substantial help*	*Totally dependent*	
27. Household responsibilities (house cleaning, cooking, washing clothes)	5	4	3	2	1	
28. Shopping (selection of items, choice of stores, payment at register)	5	4	3	2	1	
29. Handling personal finances (budgeting, paying bills)	5	4	3	2	1	
30. Use of telephone (getting number, dialling, speaking, listening)	5	4	3	2	1	
31. Travelling from residence without getting lost	5	4	3	2	1	
32. Use of public transportation (selecting route, using timetable, paying fares, making transfers)	5	4	3	2	1	
33. Use of leisure time (reading, visiting friends, listening to music)	5	4	3	2	1	
34. Recognizing and avoiding common dangers (traffic safety, fire safety)	5	4	3	2	1	
35. Self-medication (understanding purpose, taking as prescribed, recognizing side effects)	5	4	3	2	1	
36. Use of medical and other community services (knowing whom to contact, how, and when to use)	5	4	3	2	1	**Total Scale E**
37. Basic reading, writing, and arithmetic (enough for daily needs)	5	4	3	2	1	
F. Work' Skills	*Highly typical of this person*	*Generally typical of this person*	*Somewhat typical of this person*	*Generally untypical of this person*	*Highly untypical of this person*	
38. Has employable skills	5	4	3	2	1	
39. Works with minimal supervision	5	4	3	2	1	
40. Is able to sustain work effort (not easily distracted, can work under stress)	5	4	3	2	1	
41. Appears at appointments on time	5	4	3	2	1	
42. Follows verbal instructions accurately	5	4	3	2	1	**Total Scale F**
43. Completes assigned tasks	5	4	3	2	1	
				Total Score A+B+C+D+E+F =		

From "SLOF: A Behavioural Rating Scale for Assessing the Mentally Ill," by L. Schneider, & E. Struening, 1983, ***Social Work Research and Abstracts.***

APPENDIX 8 INFORMATION SHEET AND CONSENT FORM FOR STUDY PARTICIPANTS (ENGLISH VERSION)

Information Sheet for Families

Project title: Effectiveness of a mutual support group programme for families caring for a relative with schizophrenia

Investigator:
Mr. Chien Wai-tong, Associate Professor, The Nethersole School of Nursing, The Chinese University of Hong Kong, Hong Kong SAR.
The project is conducted as part of requirements in fulfilment of my Doctor of Philosophy study at the Florence Nightingale School of Nursing & Midwifery, King's College, University of London.

Aims of the study
The purpose of this study is to compare the effectiveness of a mutual support group programme, with the conventional psychiatric outpatient service, in helping primary family carers caring for a patient with schizophrenia to cope better with the demands of caregiving. You will be recruited into a newly developed mutual support group programme or a control with the conventional mental health care service you are now receiving, which has been provided by the psychiatric outpatient clinic in Hong Kong.

Intervention and data collection procedure
All participants will be administered a set of questionnaire four times in the study period: (1) during recruitment, (2) one to two weeks after intervention, (3) six months after intervention, and (4) twelve months after intervention; it allows the researcher to measure your psychosocial condition (e.g. burden of care and family functioning), and functioning and mental condition of your relative with schizophrenia. It lasts about 40 minutes.

Participants in the mutual support group are family caregivers of patients with schizophrenia attending the psychiatric outpatient clinic under study. If you agree to participate, you will have to attend 12 bi-weekly 2-hour group meetings with discussions, sharing of experience and feelings about caregiving, and reciprocal support and health information giving. The group sessions will be scheduled at your most convenience with the group consensus. Group sessions will be tape recorded, with permission from group members. You may also be invited for a 45-minute interview, which will also be tape-recorded for understanding your appraisal and feelings to the group participation. Participants in this study are assured to receive all of the usual services provided by the outpatient clinic, no matter which group you will participate.

In addition to the questionnaire and interview, you will be asked about the data on patient re-hospitalisation and family relationships biweekly during the 18-month study period.

Confidentiality
All information obtained will be kept confidential and will be used for research purpose only. Discussions within the group intervention will not be revealed to the clinic staff or other people not involved in the group programme. All tape records and research data will be stored safely in the office of the researcher and nobody can access the data without the

permission from the participants and the researcher. The final report, containing anonymous quotations, will be available to all participants on request at the end of the study.

Expected benefits

This study is important to you as a primary carer of your family member with schizophrenia. Mutual support and learning from other group members with the similar situation and concern may help to relieve feeling of distress and improve skills of caring for the patient. The findings of the study may also be important for improving the family support of patients with schizophrenia in Hong Kong.

However, there will not be any monetary reward or return during your participation in the support group or the study.

Risks

There is no physical risk expected in this mutual support group intervention. Some psychological frustration may be created in relation to sharing and discussion about the family affairs and patient care provision during the group session. The facilitator will be present in each group session to help and tackle immediately any psychological reactions or conflicts arising from the group discussion. The researcher will also work closely with the facilitator to prevent any sustained adverse reactions from the group participation, if any.

Your participation to this study is much appreciated!

Contact information for enquiry

For any questions and enquiries, please feel free to contact the researcher:
Mr. Chien Wai-tong Tel: (852) 2609 8099 or Pager: 7116 8989 A/C 399.

Consent Form for Families

THIS IS TO CERTIFY THAT I, _____ HEREBY agree to participate in the study '*Effectiveness of a mutual support group programme for families caring for a relative with schizophrenia*'.

I hereby give permission to be interviewed and the group meetings to be tape-recorded. I understand that the information given by me may be published but my name and other personal data will be kept anonymous. I am also assured that the research data will be kept confidential and only be used in this study.

I also understand that I am free to withdraw my consent and terminate my participation at any time, without any penalty.

I have been given opportunity to ask whatever questions they desire and all such questions have been answered to my satisfaction.

_____	_____	_____
Signature (Participant)	Signature (Research staff)	Signature (Witness)

Date: _____

APPENDIX 8- 2: INFORMATION SHEET AND CONSENT FORM FOR PATIENTS (ENGLISH VERSION)

Information and Consent for Patients

Project title: Effectiveness of a mutual support group programme for families caring for a relative with schizophrenia

Investigator:
Mr. Chien Wai-tong, Associate Professor, The Nethersole School of Nursing, The Chinese University of Hong Kong, Hong Kong SAR.
The project is conducted as part of requirements in fulfilment of my Doctor of Philosophy study at the Florence Nightingale School of Nursing & Midwifery, King's College, University of London.

Aims of the study
The purpose of this study is to compare the effectiveness of a mutual support group programme, with the conventional psychiatric outpatient service, in helping primary family carers caring for a patient with schizophrenia to cope better with the demands of caregiving. You will be recruited into a newly developed mutual support group programme or a control with the conventional mental health care service you are now receiving, which has been provided by the psychiatric outpatient clinic in Hong Kong.

Data collection procedure
Your family will be recruited on voluntary basis into a mutual support group programme or a control group with only the conventional psychiatric outpatient service provided by the psychiatric outpatient clinic you are attending. All participants will be administered a set of questionnaire four times during the 18-month study period to measure your and your family's psychological and social conditions.

Families in mutual support group will have to attend 12 bi-weekly 2-hour group meetings with discussions, sharing of experience and feelings, and health education. Moreover, your family will also be invited for a 45-minute interview, which will be tape-recorded for understanding their appraisal and feelings to the group participation. Participants in this study can still receive the usual services provided by the outpatient clinic.

In addition to the questionnaire and interview, you will be asked about the data on patient re-hospitalisation and family relationships biweekly during the 18-month study period.

Confidentiality
All information obtained will be kept confidential and will be used for research purpose only. Your family's participation in the study will not be revealed to the clinic staff and your attending psychiatrist. The final report, containing anonymous quotations, will be available to all participants on request at the end of the study. . All tape records and research data will be stored safely in the office of the researcher and nobody can access the data without the permission from the participants and the researcher.

This study is important for improving the family support of patients with schizophrenia, similar to you, in Hong Kong. With your consent, one primary family carer will be contacted and invitation for participation in the study.

Your participation to this study is much appreciated!

Contact information for enquiry
For any questions and enquiries, please feel free to contact the researcher:
Mr. Chien Wai-tong Tel: (852) 2609 8099 or Pager: 7116 8989 A/C 399.

Consent Form for Patients

THIS IS TO CERTIFY THAT I, _____ HEREBY agree to participate in this study.

I hereby give permission to allow the researcher and research assistants to access my personal information written in the clinical records and case notes in the psychiatric outpatient clinic under study.

I understand that the information given by my family and from the clinical records may be published, but my name and personal data will be kept anonymous. I am also assured that the research data will be kept confidential and only be used in this study.

I also understand that I am free to withdraw my consent and terminate my participation at any time, without any penalty. I have been given opportunity to ask whatever questions they desire and all such questions have been answered to my satisfaction.

_____	_____	_____
Signature (Participant)	Signature (Research staff)	Signature (Witness)

Date: _____

APPENDIX 9 SEMI-STRUCTURED INTERVIEW SCHEDULE FOR GROUP PARTICIPANTS

1. How do you feel about the participation in the mutual support group?

Prompt:
- Describe any positive feelings e.g. excitement, happiness, enjoyment or relaxing
- Describe any negative feelings e.g. unpleasant, annoying, angry or sad
- Which parts of the group meeting being most and least helpful to you?
- In addition, any content or discussion during the group to be most useful to you or your patient?

2. Recall one or two of the current impressive experiences or events during group participation?

Prompt:
- What did you feel about this experience?
- How importance is it to you ? To your family? To the group?
- Any positive or negative impact to you during the group meeting?
- What was the result? What did you learn from it?

3. Describe the process of your involvement and commitment to the group?

Prompt:
- Please comment on your involvement and commitment during the first and second session. Any changes about this during the next few sessions, also, in the 11th and 12th sessions?
- Any thing or person that assisted or facilitated your involvement or participation in the group?
- Any thing or person that could inhibit your involvement or integration to the group?
- When did you feel could trust the members and disclose your personal feelings, caregiving experiences and family events to other group members? What are the key factors causing you such change in attitude and behaviour?

4. What are the benefits you obtained from the group participation?

Prompt: Please describe any of the events or comments relating to:
- Instrumental: practical assistance & material support

- Emotional or esteem support
- Information support
- Problem solving
- Social relationship or companionship

5. What are the negative aspects of the group?

Prompt:
- Time inflexibility and consuming
- Inadequate time or number of sessions
- Negative experiences or feelings
- Support providing more than receiving
- Reduced hope for patient recovery
- Ineffective coping with caregiving role and related stress
- Lowered self-esteem

6. Describe any additional social support or friendship development outside the group meeting with the group members, or non-member. Do you think this is important to you? Please comment.

7. Will you continue to participate in the group if available? Why or why not?

8. What do you think about the needs of a leader/facilitator in the group?

Prompt:
- What do you think about the role of the facilitator in your group? Did he/she perform the expected role?
- Was the leader a formal or informal one? If yes, what was the leader expected to do for the group?
- Are you satisfied with the way of facilitation throughout the group meetings? Are there any suggestions for improvements?

9. Are you satisfied with the usual outpatient services provided?

Prompt:
- to patient; Please explain why you feel satisfied or not.
- to family; Please explain why you feel satisfied or not.
- what can you suggest for improvement?

APPENDIX 10 SPSS OUTPUTS OF MANOVA, FOLLOWED BY STEP-DOWN ANALYSES OF FIVE CORRELATED OUTCOME VARIABLES (SYNTAX & SELECTED OUTPUTS FROM SPSS)

```
MANOVA
burden_1 burden_2 burden_3 burden_4 slof_1 slof_2 slof_3 slof_4 famfun_1 famfun_2 famfun_3
famfun_4 suprt_1 suprt_2 suprt_3 suprt_4 satsup_1 satsup_2 satsup_3 satsup_4
        By group (1,2)
/WSFACTORS = time (4)
/WSDESIGN = TIME
/MEASURES = burden slof famfun suprt satsup
/RENAME=burden, burden_LIN, burden_QUAD, burden_CUBIC
        slof, slof_LIN, slof_QUAD, slof_CUBIC
        famfun, famfun_LIN, famfun_QUAD, famfun_CUBIC
        suprt, suprt_LIN, suprt_QUAD, suprt_CUBIC
        satsup, satsup_LIN, satsup_QUAD, satsup_CUBIC
/WSDESIGN = TIME
/PRINT = SIGNIF(UNIV, STEPDOWN, EFSIZE) ERROR(CORR) HOMOGENEITY(BOXM)
/PLOT
/DESIGN = group.
```

Note: Burden: FBIS score; slof: SLOF score; famfun: FAD score; suprt: SSQ6- number of support person; satsup: SSQ6- support satisfaction.

1. Multivariate analysis of variance of five outcome variables as a function of group, time and group by time interaction

* * * * A n a l y s i s o f V a r i a n c e * * ** *

EFFECT .. GROUP
Multivariate Tests of Significance (S = 1, M = 1 1/2, N = 34)

Test Name	Value	Exact F	Hypoth. DF	Error DF	Sig. of F
Pillais	.82365	65.38666	5.00	70.00	.000
Hotellings	4.67048	65.38666	5.00	70.00	.000
Wilks	.17635	65.38666	5.00	70.00	.000
Roys	.82365				

Note.. F statistics are exact.

- -

EFFECT .. TIME
Multivariate Tests of Significance (S = 1, M = 6 1/2, N = 29)

Test Name	Value	Exact F	Hypoth. DF	Error DF	Sig. of F
Pillais	.82266	18.55497	15.00	60.00	.000
Hotellings	4.63874	18.55497	15.00	60.00	.000
Wilks	.17734	18.55497	15.00	60.00	.000
Roys	.82266				

Note.. F statistics are exact.

- -

Tests involving 'TIME' Within-Subject Effect.
EFFECT .. GROUP BY TIME
Multivariate Tests of Significance (S = 1, M = 6 1/2, N = 29)

Test Name	Value	Exact F	Hypoth. DF	Error DF	Sig. of F
Pillais	.95486	84.61790	15.00	60.00	.000
Hotellings	21.15447	84.61790	15.00	60.00	.000
Wilks	.04514	84.61790	15.00	60.00	.000
Roys	.95486				

Note.. F statistics are exact.

- -

2. **Univariate analyses of variance of five outcome variables for effects of group, time and group by time interaction**

EFFECT .. GROUP (Cont.)
Univariate F-tests with (1,74) D. F.

Variable	Hypoth.SS	Error SS	Hypoth.MS	Error MS	F	Sig. of F
BURDEN	2869.5921	8273.5395	2869.5921	111.8046	25.6661	.000
SLOF	39768.1875	15467.6118	39768.1875	209.0218	190.2586	.000
SUPRT	54.8165	89.9109	54.8165	1.2150	45.1161	.000
SATSUP	84.9173	64.2591	84.9173	.8684	97.7897	.000
FAMFUN	1089.0581	262.4251	1089.0581	3.5463	307.0983	.000

- -

EFFECT .. TIME (Cont.)
Univariate F-tests with (1,74) D. F.

Variable	Hypoth. SS	Error SS	Hypoth. MS	Error MS	F	Sig. of F
BURDEN	97.01053	513.49737	97.01053	6.93915	13.98017	.000
SLOF	1478.29013	4049.62763	1478.29013	54.72470	27.01322	.000
SUPRT	5.48040	27.96994	5.48040	.37797	14.49949	.000
SATSUP	.67663	38.38575	.67663	.51873	1.30442	.257
FAMFUN	113.93475	64.41629	113.93475	.87049	130.88570	.000

- -

EFFECT .. GROUP BY TIME (Cont.)
Univariate F-tests with (1,74) D. F.

Variable	Hypoth. SS	Error SS	Hypoth. MS	Error MS	F	Sig. of F
BURDEN	681.79211	513.49737	681.79211	6.93915	98.25292	.000
SLOF	17361.0322	4049.62763	17361.0322	54.72470	317.24309	.000
SUPRT	30.86401	20.96994	30.86401	.35797	42.82244	.001
SATSUP	28.30117	22.38575	28.30117	.48873	35.97054	.001
FAMFUN	617.90326	64.41629	617.90326	.87049	709.83349	.000

- -

3. Step-down analyses of five ordered outcome variables for group, time and group by time interaction

EFFECT .. GROUP (Cont.)
Roy-Bargman Stepdown F - tests

Variable	Hypoth.MS	Error MS	StepDown F	Hypoth.DF	Error DF	Sig.of F
FBIS	2845.0658	110.8739	25.6604	1	74	.000
FAMFUN	68.6199	1.8160	37.7855	1	73	.000
SLOF	20346.8956	165.1477	123.2042	1	72	.000
SUPRT	2.2355	.7205	3.9767	1	71	.010
SATSUP	.0473	.2944	.1608	1	70	.690

- - - -

APPENDIX 11 A WORKED EXAMPLE OF QUALITATIVE DATA ANALYSIS

This worked example of qualitative data analysis was to illustrate the steps or procedures used to analyse the interview and group session data collected in this study. The analysis of these data aimed at exploring the therapeutic mechanisms of the mutual support group, as perceived by the family carers who underwent the group intervention. As Miles and Huberman's (1994) six-stage procedure of qualitative data analysis was used, the steps of data analysis guided by these stages are shown in the following tables and illustrated by an example of verbatim data. The first table also indicates how these six-stage procedures corresponded to the steps of thematic analysis as suggested by Morse (1997), from coding of interview and group session data to theme matching and condensation and finalising the list of themes illustrated by verbatim data.

In the first table, the first two steps of analysis: (a) getting familiar with the diversity of the verbatim data collected and affixing codes and remarks to each transcript and (b) sorting and sifting through the codes and interview data to identify similarities, differences and patterns between the codes and noting the recurrent themes emerging from transcripts, are illustrated. Some selected codes from the interview and group session transcripts are listed and the recurrent codes in relation to '*shared goals*' and '*agreed tasks/objectives with group consensus*' are highlighted for illustration of how these two steps (and the other four steps in the later description) actually worked.

Stages of data analysis	**Coding of interview and group session data**		**Identifying themes that emerged from each interview and group session transcript**		**Comparing and contrasting themes between each set of interview and group session transcripts, independently**	**Theme matching & condensat-ion among all data**	**Finalising the themes illustrated by verbatim data**
Six-stage procedures suggested by Miles and Huberman (1994)	***Getting familiar with diversity of verbatim data collected and affixing codes and remarks***	***Sorting and sifting through the codes and data; Noting recurrent themes or categories emerging from the transcripts***	Elaborating a set of generalisations that cover the consistencies discerned in the interview and group session data	Isolating the patterns and clustering commonalities and differences between the themes and creating a thematic index to all transcripts	Reorganising, contrasting and mapping the categories and themes identified, making interpretations and providing explanations		Finalising the materials, re-examining the data if necessary, and drawing conclusions

Affixing codes from interview and group session data

Selected initial coding of interviews and group session data illustrated the recurrent codes related to *shared and common goals,* which are highlighted in *italic and bolded* fonts as follows:

"I experienced an increased sense of unity in my group. All the members were united with each other in a common purpose. We enjoyed excellent teamwork. Our aim was clear and this made us to work purposively to improve our family caregiving... I mean, if we have agreed tasks and objectives to be achieved…with group discussion and consensus, we can unite together in a powerful force. Therefore, I think it is very important for a support group to have some activities and tasks, which focused on family or patient care in each session" (Interview, Carer 10, para. 10)
Coding: sense of unity, ***shared goals, agreed tasks/objectives with group consensus***, activities and task to be achieved or focused

"We divide up the workload and share it among our members. We have to remember our common goals and concerns in learning how to improve my family care and also share our worry and other feelings in the group… thus we feel support from each other to achieve our target activities. We try to avoid giving people fixed responsibilities, and someone is in charge of the activity… or our group task. We support the one in-charge and are ready to give them help. A sense of unity and mutual support and help had been established. Although our programme often delayed because of unexpected active participation in sharing and discussion and rehearsals of caregiving situations but… to me was not a serious problem." (Interview, Carer 15, para. 56).
Coding: task assignment, ***common goals and concerns***, mutual support, sense of unity, delay in achieving goal/task

"Our group was very emphasised on goal or task achievement… we agreed on some specific activities or discussion in each session, which were our similar targets and objectives of achievement in this group, with reference to the session theme in the protocol… As a result, I learned a lot about caregiving from communicating with those enthusiastic group mates… during and outside the group sessions. These valuable experiences and practical help from them certainly could not obtain from other sources, even health services available in the clinic." (Interview, Carer 20, paragraph 50).
Coding: emphasis on goal or task achievement, ***similar targets and objectives***, protocol adherence, learning inside and outside group

"If we have a common goal, we will unite with each other more easily. It is good for us to aim at one to two targets or tasks in the early session and focus our energies into it… We have not enough time to talk about everything we concern or need and therefore we have to focus on a few important common concerns to work on… It is easy for us to find out our common goal because we come together with similar feelings and experiences concerning the mental illness and its care. Most important is that all people in this group share the same experiences as family carers." (2nd group session, Carer 8, para. 49).
Coding: ***setting common goals***, aiming at one or two targets/ tasks, sharing similar experience/feeling

"Being able to tell our worries to each other openly, and baring our hearts to each other are very important in our group. Nobody else in our life understands our concerns in family care. Before coming here, I constantly felt as if I have to bear the responsibility and consequences of my child's illness on my own. But now, our group (your support) quickly take away my burden and I deeply moved when I shared with you about my similar problems as yours and all of you discuss with me how to deal with them one by one… I am more focusing on the common and agreed goals or objectives in each session and know what I need to talk about and learn from the group… I think I have gained a lot of benefits from this focused discussion and work…" (3rd group session, Carer 13, para. 33)
Coding: Sharing worries, removing burden, similar problems, specific topics of discussion, ***focusing on common and agreed objectives***

The third stage of analysis is to elaborate a set of generalisations that cover the consistencies discerned in the interview data and group session data in this study. As indicated in the table below, the recurrent codes (grouped with similar meaning) were extracted from the interview and group session data, independently, and the tentative category '***common goals and concerns'*** was identified and illustrated by the verbatim data used in the previous stages, and those in the other transcripts. Another two sets of recurrent codes regarding the tentative categories: 'goal/task orientation' (item 2) and 'sense of cohesiveness' (item 3) are listed for more understanding about the analysis work in this stage.

Six-stage procedures suggested by Miles and Huberman (1994)	Getting familiar with diversity of verbatim data collected and affixing codes and remarks	Sorting and sifting through the codes and data; Noting recurrent themes emerging from the transcripts	***Elaborating a set of generalisations that cover the consistencies discerned in the interview and group session data***	Isolating the patterns and clustering commonalities and differences between the themes and creating a thematic index to all transcripts	Reorganising, contrasting and mapping the categories and themes identified, making interpretations and providing explanations	Finalising the materials, re-examining the data if necessary, and drawing conclusions

II. Sorting and grouping recurrent codes and considering potential categories or themes

Recurrent codes (grouped with similar meaning) extracted from the interview and group session data independently, are sorted and grouped in categories. One initial category – Common goals and concerns (item 1 below) is identified and illustrated by the data used in the first table, and also data from other transcripts. Another two set of recurrent codes relating to initial categories: goal/task orientation (item 2) and sense of cohesiveness (item 3) are also listed below.

1. **Initial theme/category: Common goals and concerns**

   From interview data:

   Shared goals (Interview, Carer 10, para. 10, 37, 49, 88, & 103), agreed objectives with group consensus (Interview, Carer 10, para. 10), common goals and concerns (Interview, Carer 15, para. 56), similar targets and objectives (Interview, Carer 20, para. 50 & 52)

   From group session data:

   Setting common goals (2nd group session, Carer 8, para. 49), focusing on common and agreed objectives (3rd group session, Carer 13, para. 33)

   Similar codes in other transcripts:

   From Interview data:

   Group goals and agreed actions (Interview, Carer 1, para. 30, 32, 40, & 44), tasks agreed to be achieved (Interview, Carer 3, para. 18, 20, 24, & 26), common concerns and needs (Interview, Carer 6, para. 8, 10, 20, & 22), explicit expectations and goals to be achived in group (Interview, Carer 10, para. 38, 40 & 42), simple and clear objectives in common (Interview, Carer 16, para. 10, 12, 18, & 20), similar goals of learning (Interview 18, para. 6, 8, 15, 17, & 19), group consensus and common goals (Interview, Career 20, para. 22, 24, 38, 40, & 66)

   From group session data:

   Agreed direction and objectives of group work (2nd group session, Carer 5, para. 55 & 59), items agreed to be achieved in group sessions, learning needs and goals in common (4th group session, Carer 8, para. 24, 25 & 40), established group direction and consensus (4th group session, Carer 13, para. 20 & 78), agreed objectives and group consensus (4th group session, Carer 18, para. 60, 62 & 66), clear direction and goal in common (5th group session, Carer 2, para. 68 & 70), not being in loss when reminding ourselves the agreed objectives (5th group session, Carer 16, para. 40)

   ***unclear objectives and topics of discussion in the first session(2nd session, Carer 15, para. 13 & 14)*

2. **From interview data:**
   Activities and tasks to be achieved or focused (Interview, Carer 10, para. 10), task assignment, goal/task focusing (Interview, Carer 15, para. 56), emphasis on goal or task achievement (Interview, Carer 20, paragraph 50)
   From group sessions:
   Aiming at one or two targets/ tasks in each session (2nd group session, Carer 8, para. 49), specific topics of discussion, focusing on specific objectives in each session (3rd group session, Carer 13, para. 33), achieving three targets or cover a few areas of discussion in each session (8th group session, Carer 17, para. 98),
   ***Over demanding and stressful in target accomplishment (10th group session, Carer 18, para. 103)*

3. **From interview data:** sense of unity, cohesiveness, connectedness, enjoyed the friendship and relatedness with members, good connections between group mates during and outside meetings, experience of close bonding and connections, frequent contacts and psychological support.
   From group session data: sense of unity, closely related to each other, feeling good to be with other members, feeling of accompanying with other family carers to tackle problems, feeling of cohesion and mutual support between members, inter-related and closer relationship than other relatives or friends

*** indicates the codes that contained data contradicting with the others in the category.*

The fourth step of analysis is to isolate the patterns and clustering commonalities and differences between the themes and categories that emerged from the interview and group session data, and create a thematic index to all transcripts. The following table indicates a sample of thematic index for one of the interviews and group sessions. The tentative categories concerning 'shared goals' and 'agreed tasks/ objectives with group consensus' used in the previous illustration are highlighted.

Six-stage procedures suggested by Miles and Huberman (1994)	Getting familiar with diversity of verbatim data collected and affixing codes and remarks	Sorting and sifting through the codes and data; Noting recurrent themes emerging from the transcripts	Elaborating a set of generalisations that cover the consistencies discerned in the interview and group session data	***Isolating the patterns and clustering commonalities and differences between the themes and creating a thematic index to all transcripts***	Reorganising, contrasting and mapping the categories and themes identified, making interpretations and providing explanations	Finalising the materials, re-examining the data if necessary, and drawing conclusions

III. Identifying patterns or categories that emerged from interview and group session data, respectively.

A sample of thematic index for one of the interviews (Carer 10) and one of the group sessions are indicated below:

Interview, Carer 10

1. Positive group characteristics

1a Shared goals (para. 10, 37, 49, 88, & 103);

***** Not adequate guidance for goal setting (para. 50 & 52)***

1b Agreed objectives with group consensus (para. 10); High level of group consensus and similar viewpoints (para. 21, 47, 96, & 109)

1c Sense of unity and mutual concern (para. 44, 67, 81, & 110)

1d Working effectively on one target in each session (para. 19, 69, 77, & 104)

1e Adequate information of schizophrenia and its treatment (para. 60, 69, 90, & 122)

1f Clear statement of help seeking strategies (para. 16, 20 & 37)

1g Nurtured competency and psychological adaptation of caregiving role (para. 58, 69, 90, & 102)

1h Openly expressed my concerns and needs (para. 14, 16 & 83)

*** requesting more attention to individual caregving problem (para. 40 & 42)*

2. Negative group characteristics
3. Individual changes throughout the group participation
4. Structural factors influencing the group effect
5. Task achievement during group session
6. Support obtained outside group
7. Learning in patient and family care
8. Difficulties in group participation
9. Development of the whole group throughout 12 group sessions
10. Recognition of community support resources
11. Building more effective coping skills for caregiving

Fifth group session

1. Positive group characteristics

1a Close and supportive relationship (Carer 7, para. 30; Carer 16, para. 48 & 79)

1b Focusing on agreed objectives (Carer 4, para. 7, 29 & 67; Carer 18, para. 102)

1c Work closely to achieve goals (Carer 10, para. 29; Carer 19, para. 33, 34 &76)

1d Understanding of one another's concerns and health needs (para. 14, 33, 48, & 50)

1e Importance of information giving for the mental illness and patient symptoms (Carer 5, para. 59, 78, 92, & 115)

1f Inducing confidence and power in caring for family members (Carer 8, para. 25, 40 & 70; Carer 7, 88 & 90)

1g Respect for each family's difficulties and weaknesses in caregiving (Carer 12, para. 10 & 30; Carer 13, para.70 & 83)

1h Developed good sense of cohesiveness among members (Carer 2, para. 10 &25; Carer 14, para. 94, 110 & 115)

2. Commonalities in caregiving and family situation
3. Feeling of self-efficacy and enabling
4. Achieving one or two objectives in each session
5. Building trust and mutual support at the early stage
6. Negative pressure form experienced members
7. Intensive emotional reactions and conflicts
8. Support obtained from other family members
9. Autonomous and flexible group structure
10. Professional support outside group
11. Inducing hope and enthusiasm in patient recovery
12. Coping strategies of the illness and family and patient care
13. Difficulties encountered in group participation
14. Resolution of negative feelings and conflicts between family members
15. Interest in group continuation in latter sessions

** *indicates the codes that contained data contradicting with the others in the same theme.*

The fifth step of analysis is to reorganise, contrast and map the themes and sub-themes identified, making interpretations and providing explanations/evidence for them. Therefore, as indicated in the table below, the tentative themes and sub-themes that emerged from the interview and group session data were reorganised and condensed into more meaningful themes and sub-themes, which can best represent all the verbatim data concerned. The specific category 'group ideology and consensus' is highlighted in the table for illustration of how this category was established through the previous steps of analysis. This step, together with the sixth step of analysis, were also repeated to identify the therapeutic mechanisms of the support group, by comparing and reorganising the themes and sub-themes with consideration to the meaning of the data, making interpretation of the connectedness and relationships between these themes and sub-themes. The finalised themes and sub-themes in relation to the mechanisms contributing to the therapeutic values of participation in the support group, as perceived by the family carers, were linked with the stage(s) of the group development, in which the themes emerged from the group session data, and also with the results of the family carers' psychosocial health outcomes.

Six-stage procedures suggested by Miles and Huberman (1994)	Getting familiar with diversity of verbatim data collected and affixing codes and remarks	Sorting and sifting through the codes and data; Noting recurrent themes emerging from the transcripts	Elaborating a set of generalisations that cover the consistencies discerned in the interview and group session data	Isolating the patterns and clustering commonalities and differences between the themes and creating a thematic index to all transcripts	***Reorganising, contrasting and mapping the categories and themes identified, making interpretations and providing explanations***	Finalising the materials, re-examining the data if necessary, and drawing conclusions

First round

IV. Reorganising and mapping categories and themes, making interpretations with verbatim data support
Reorganisation and condensation of themes and categories that emerged from the interview and group session data was performed and the sample work for the category 'group ideology and consensus' and other categories under the theme 'positive group characteristics' are illustrated as below: 1. Positive group characteristics ***1a Group ideology and consensus*** [Int = 18 & Grp = 10; summarised from, for examples: simple and clear goals (Interview, Carer 4, para. 24 & 30), working on explicit main targets (4th group session, para. 14 & 60), focusing on agreed objectives (5th group session, para. 7, 29, 67, & 102), explicit and simple goals (Interview, Carer 3, para. 37, 49, 88, & 103), agreed goals and action plans (Interview, Carer 8, para. 30, 70 & 91),

s***hared goals (Interview, Carer 10, para. 10, 37, 49, 88, & 103), agreed objectives with group consensus (Interview, Carer 10, para. 10); High level of group consensus and similar viewpoints (Interview, Carer 10, para. 21, 47, 96, & 109), goal-directed activities (6th group session, para. 7, 18, 33, & 60), shared goals and agreed objectives (Interview, Carer 10, para. 10, 47, 96, & 109***), making consensus on group behaviour and activities (Interview, Carer 11, para. 40 & 42), required consensus in group goals and behaviour (Interview, Carer 15, para. 12, 30, 32, & 38), agreement on rules, activities and topics of discussion (Interview, Carer 18, para. 30, 32, 40, & 42)] #

[*Contradictive data identified*: Inadequate guidance for goal setting (Interview, Carer 3, para. 50 & 52), unclear objectives in a few sessions (Interview, Carer 6, para. 25, 27 & 29)]

1b Relational climate and dynamics

- ***Sense of cohesiveness*** [Int = 15 & Grp = 10; summarised from, for examples: sense of unity and mutual concern (Interview, Carer 3, para. 44, 67, 81, & 110), strong cohesion and intimate relationship between members (Interview, Carer 5, para. 20, 22, 37, 39), ***feeling of unity and relatedness (Interview, Carer 10, para. 10,*** 12, 18, & 20), interdependent to one another to learn caregiving (Interview, Carer 11, para. 28, 30, 60, & 62), closely linked and related to each other (Interview, Carer 14, para. 30, 32, 48, & 50), close and supportive relationship (5th group session, para. 30, 48 & 79), working closely to achieve goals (5th group session, para. 29, 33, 34, & 76), developed good sense of cohesiveness among members (5th group session, para. 10, 25, 94, 110, & 115)]
- ***Task focusing or orienting*** [Int = 20 & Grp = 6; summarised from, for examples: task achievement in group session (Interview, Carer 3, para. 33, 35 & 70), working effectively on one target in each session (Interview, Carer 3, 19, 69, 77, & 104), achieved a few objectives in each session (5th group session, para. 44, 46, 68 & 70), focusing on a few achievable targets in each session (6th group session, para. 33, 35 & 70), ***having agreed tasks to be achieved (Interview, Carer 10, para. 10***, 42, 44, 77 & 79), setting and focusing on one to two objectives (Interview, Carer 16, para. 33, 35, 66, & 68)]
- Open expression and personal disclosure [Int = 15 & Grp = 5; summarised from, for examples: openly expressed concerns and needs (Interview, Carer 3, para. 12, 14 & 83), willing to disclose personal events (Interview, Carer 7, para. 22, 24, 50, 52, & 79), open disclosure of family situation (Interview, Carer 17, para. 44, 46, 55, & 57), learned to share own feelings and situation (6th group session, para. 40, 42 & 79), eager to share own views and experiences (7th group session, para. 41, 43, 91, & 99)]

  [*Contradictive data identified*: Too embarrassed experiences not to be disclosed (Interview, Carer 13, para. 58 & 60), selective in experience sharing (Interview, Carer 17, para. 55, 57 & 100)]

  [*Cross linking with the theme* - Building trust relationship, illustrated by examples: sharing own secrets to those you trusted (Interview, Carer 14, para. 66, 68, 82, & 84), open disclosure based on trusting other members (Interview, Carer 2, para. 11, 13, 44, & 46)]

1c Informational support [Int = 16 & Grp = 7; summarised from, for examples: adequate information of the illness (Interview, Carer 3, para. 19, 69, 77, & 104), recognition of community support resources (Interview, Carer 3, para. 77 & 79), important to have information sharing (Interview, Carer 7, para. 19, 21, 55, & 80), importance of information giving (5th group session, para. 59, 78, 92, & 115), helpful for information sharing (10th group session, para. 78, 80, 102, &104)]

1d Feeling of empowerment [Int = 14 & Grp = 5; summarised from, for examples: Felt competent and adapted to caregiving role (Interview, Carer 3, para. 58, 69, 90, & 102), enabling and empowered to fulfil caregiving tasks (Interview, Carer 9, para. 66, 68, 91, 92), feeling of self-efficacy and enabling (5th group session, para. 78, 80, 82, 84), inducing confidence and power in caregiving (5th group session, para. 25, 40, 70, 88, & 90), understanding of own strengths and ability for caregiving (7th group session, para. 66, 68, 90, & 104)
[*Cross linking with the theme* – Informational support, illustrated by examples: felt empowered by knowledge gained (Interview, Carer 8, para. 60, 62, 102, & 104), adequate knowledge and skills for self-care and caregiving (Interview, Carer 12, para. 18, 20, 42, & 44), knowledge of the illness enhanced competence of caregiving (9th group session, para. 77, 79, 86, & 88)]

Int = No. of interview in which the category was identified; Grp = No. of group session in which the category was identified.
# Tentative sub-themes from the thematic index of individual interview or group session are summarised in the parentheses

The sixth step of analysis is to finalise the materials (the themes and sub-themes identified), re-examine the data if necessary and draw conclusions. The finalised list of themes and sub-themes that emerged from the interview and group session data collected in this study is presented in the following table.

Six-stage procedures suggested by Miles and Huberman (1994)	Getting familiar with diversity of verbatim data collected and affixing codes and remarks	Sorting and sifting through the codes and data; Noting recurrent themes emerging from the transcripts	Elaborating a set of generalisations that cover the consistencies discerned in the interview and group session data	Isolating the patterns and clustering commonalities and differences between the themes and creating a thematic index to all transcripts	Reorganising, contrasting and mapping the categories and themes identified, making interpretations and providing explanations	***Finalising the materials, re-examining the data if necessary, and drawing conclusions***

V. Finalised the list of themes and categories that emerged from the interview and group session data

1. Important factors influencing group development

1a Building mutual trust and acceptance in the first group phase
- establishing trust relationship with members and its difficulties
- adaptation of group discussion and behaviour
- open disclosure of own feelings and concerns
- establishing simple and realistic common goals
- willing to listen to and helping others

1b Resolution around power, control and decision making within group (2nd group phase)
- minimal power struggle
- deciding on the topics of discussion
- feeling of control over group participation

1c Learning to adopt new coping methods and skills for caregiving (3rd group phase)
- effective learning about the illness and caregiving
- difficulties of carers in adopting new caregiving role
- appropriate length of group intervention

1d Perception of group members for future life with adequate family support (4th group phase)
- satisfaction to mutual support and goal achievement
- maintaining linkage and meetings between members in future
- talking about separation anxiety and uncertainty
- encouraging independence in future caregiving

2. Individual changes in identity, perception and coping ability for caregiving

2a Changes in personal identity in relation to caregiving
- adoption of a positive personal identity of being a family carer
- importance and responsibility in caring the patient

2b Changes in perception of mental illness and its care
- making sense of the illness reality and family role of caregiving
- letting go of useless efforts to improbable changes of patient care
- exchange ideas with respect and reframing of life problems
- positive perception of the illness and its care

2c Adoption of new and effective role and coping skills for caregiving
- gaining from members' experiential knowledge of resolution of life problems
- learning effective ways of communication with patient
- adopting a few effective coping methods of caregiving
- importance of trust relationship in group sharing

3. Positive and negative group characteristics

3a Group ideology and consensus
- ***explicit shared goals and objectives***
- ***High level of group consensus in objectives, tasks and behaviour***

3b Relational social climate
- sense of cohesiveness
- goal or task orientation
- openness of self in group discussion

3c Informational support and feeling of empowerment
- benefits from experiential knowledge and information materials of the illness and its care
- feeling enthusiastic to reach out to people and cope with caregiving situation
- learning to overcome negative feelings from unresolved problems

3d Inhibitory factors influencing group development
- irregular or low group attendance
- negative and high peer pressure and dominance in group
- over-expression of intense emotions and conflicts

4. Effects of group structure and external environment

4a Non-hierarchical and autonomous group structure
- autonomous, small sized, single-level group with stable attendance
- informal role of group maintenance and coordination

4b Perception of professional involvement and support
- important interaction and linkage with health professionals
- referrals to appropriate family support services if needed
- appropriate utilisation of services
- partnership in patient care provision

4c Social support form family members and people outside group
- outside group network as the sources of immediate support to caregiving
- more comfortable to discuss about personal issues to close friends than family

The first theme that emerged from the data explains the accounts of the group participants on the important factors influencing each of the five phases of group development adopted from the suggested framework of self-help groups by Wheelan (1994) and Kimberly (1997) (refer to Section 4.7 in Chapter 4 for detail information of the five group phases). The second, third and fourth themes indicate that important factors perceived by the family carers that might contribute their benefits gained from the group participation or influence the success of the support group used in this study in terms of three levels – individual, group and social environment. Several categories are also identified to provide a clear account of the perceived therapeutic factors of the support group in each level; for example, the second theme for individual

level consists of three categories: (1) changes in personal identity in relation to caregiving; (b) changes in perception of mental illness and its care; and (c) adoption of new and effective role and coping skills for caregiving.

The fifth and sixth step of analysis were then repeated again to identify the themes and sub-themes contributing to the therapeutic mechanisms of the support group used in this study. The themes and sub-themes finalised in the above list were re-examined and reorganised to find out the possible relationships between them in relation to the therapeutic actions and values of the support group as perceived by the family carers, as well as their connectedness with the stages of group development and the data about verbal comments of the group participants on the benefits gained and their own psychosocial health conditions. By making interpretation of the meaning of the data and the inter-relationships between the themes and sub-themes identified, four therapeutic mechanisms of the support group were generated (see Figure 8.1 in Chapter 8). One of the therapeutic mechanisms (**M2**: Establishing and focusing on clear, realistic common goals and tasks within group) is presented below in the table for illustration of how these mechanisms were established.

Six-stage procedures suggested by Miles and Huberman (1994)	Getting familiar with diversity of verbatim data collected and affixing codes and remarks	Sorting and sifting through the codes and data; Noting recurrent themes emerging from the transcripts	Elaborating a set of generalisations that cover the consistencies discerned in the interview and group session data	Isolating the patterns and clustering commonalities and differences between the themes and creating a thematic index to all transcripts	Reorganising, contrasting and mapping the categories and themes identified, making interpretations and providing explanations	***Finalising the materials, re-examining the data if necessary, and drawing conclusions***

Second round

Themes and sub-themes	***Stage of group development in which the theme identified***	***Examples of verbal comments on the benefits gained and their health conditions***
Re-examining and reorganising themes and sub-themes in relation to the importance of clear and realistic goals: 3a Group ideology and consensus - **Explicit shared goals and objectives** - High level of group consensus in objectives, tasks and behaviour	In the first stage	"Clear goals and objectives set at the early stage of the group provided us a clear direction for learning and areas of discussion and practice." (10th group session, Carer 10) "I had great improvement in my family relationship and communication because we worked very hard to achieve the goals and objectives set in the early sessions." (Interview, carer 5, para. 62) "Most of the set goals were very focused on our concerns and problems in caregiving. We could learn how to solve these problems by achieving the goals." (Interview, Carer 13, para. 69)

1a Building mutual trust and acceptance - Open disclosure of own feelings and concerns - **Establishing simple and realistic common goals** - Willing to listen to and helping others	In the first stage	"Building trust and respect in the first most important thing to do before we can discuss about our problems and concerns in the group. We could establish common gorals because we trusted each other and talked openly about our common problems in caregiving..." (Interview, Carer 9, para. 32) "We established some simple and realistic goals first at the start so that we can achieve it earlier and, through this achievement, our truth and cooperation between each other might be strengthened. Then, we could establish goals, which were more important in our caregiving." (8th Group session, Carer 15) "Achievement of the common goals and tasks could increase my confidence in problem solving and be useful in my learning of family caregiving. I felt more committed to the group as we understood what and how to help each other in attending the group meetings and informal contacts outside the group." (Interview, Carer 7, para. 50)
1b Resolution around power, control and decision making within group - Minimal power struggle - Deciding on the topics of discussion	In the second stage	"We could suggest and decide what we would discuss in the support group. This can help us to establish our preferred goal and direction for discussion and learning in the group." (7th group session, Carer 8) "We had little struggle about who lead the group or which goals to be achieved first. We decide the things together and find out the common goals and concerns."
3b Relational social climate - Goal or task orientation - Openness of self in group discussion	In the second stage	"The group emphasised on discussion and identifying ways to deal with our common problems in caregiving. We openly discuss about our concerns and experiences in tackling the problems, no matter we failed or succeeded. I felt this positive way of problem solving helped me a lot in learning about the skills for caregiving." (Interview, Carer 10, para. 38) "Our open disclosure in the group meetings helped us understand our needs and concerns and also establish the agreed targets to be achieved. We can help each other in the process of tackling the problems that we all encountered in our families." (7th group session, Carer 16)

Making interpretation of the relationships between the themes and sub-themes concerning the importance of clear and realistic goal, providing explanation of the relationships with support from the data: The common theme: **Explicit shared goals and objectives** Related themes and sub-themes: 1. Group ideology and consensus - High level of group consensus in objectives, tasks and behaviour 2. Building mutual trust and acceptance - Open disclosure of own feelings and concerns 3. Relational social climate - Goal or task orientation - Openness of self in group discussion	In the first stage In the first stage In the second stage	The interview and group session data supported that establishing and focusing on clear, realistic goals and tasks within the support group was very important for the participants in gaining benefits on learning about problem solving, reciprocal support and assistance and coping skills for caregiving. As a result, the carers indicated great improvements in caregiving and problem solving skills, as well as in family functioning. Achievement of the common goals could motivate their commitment and learning to offer help for each other in the group.

Finally, in the repeated sixth stage of analysis, the four therapeutic mechanisms of the mutual support group were identified from the themes and sub-themes that emerged in the first round of the fifth and sixth stage of analysis. The Mechanism 2 is presented below for illustration.

Six-stage procedures suggested by Miles and Huberman (1994)	Getting familiar with diversity of verbatim data collected and affixing codes and remarks	Sorting and sifting through the codes and data; Noting recurrent themes emerging from the transcripts	Elaborating a set of generalisations that cover the consistencies discerned in the interview and group session data	Isolating the patterns and clustering commonalities and differences between the themes and creating a thematic index to all transcripts	Reorganising, contrasting and mapping the categories and themes identified, making interpretations and providing explanations	***Finalising the materials, re-examining the data if necessary, and drawing conclusions***

Mechanism	*Related factors identified in the stage of group development*	*Related psychosocial health outcomes*
M2: Establishing and focusing on clear, realistic common goals and tasks within group - Discuss and agree on explicit goal and direction in the first and/or second session - Task orientation and focusing on goal achievement	Stage 1 to 2 – Orientation and engaging in the group; Being aware of own feelings and concerns regarding caregiving - Setting clear realistic common goals - Perception of better control over own life situation	- Creating altruism and commitment to achieve the purposes of participation in the group - Enhanced learning of problem solving and caregiving skills - Improved family functioning

APPENDIX 12 APPROVAL LETTER FROM THE RESEARCH ETHICS COMMITTEE

THE CHINESE UNIVERSITY
OF HONG KONG

FACULTY OF MEDICINE
SHATIN. NT. HONG KONG

香 港 中 文 大 學
醫 學 院
香 港 新 界 沙 田

GENERAL OFFICE FAX. NO. 醫學院辦事處傳真： (852) 2603 6958

Your Ref:

Our Ref: FM/C/13 – CRE-2001.270

Mr. CHIEN Wai Tong
Dept. of Nursing
CUHK

1 August 2001

Dear Mr. Chien,

I write to inform you that ethical approval has been given for you to engage in the project named below:

Project Title : **"Evaluation of A Mutual Support Group for Family Carers of Patients with Schizophrenia" (ref. No. CRE-2001-270)**

Investigator(s) : **Mr. CHIEN Wai Tong (Assistant Professor), Dept. of Nursing, CUHK**
Ms CHAN Sally (Assistant Professor), Dept. of Nursing, CUHK

Duration : **24 months**

Location of Study : **1) Prince of Wales Hospital**
2) Alice Ho Miu Ling Nethersole Hospital

Conditions by Clinical Research Ethics Committee (if any): **Nil**

It will be much appreciated if the completion of the project will be reported to the Committee in due course.

Yours sincerely,

Andrew Chan
Secretary
Clinical Research Ethics Committee

cc. Mrs Alice Yip – RTAC (ref. Health Care & Promotion Fund)

院長
鍾尚志教授
Dean
Professor S.C. Sydney Chung
LRCP & SI; MBBCh; BAO; MD;
FRCS(Edin & Glasg); FRCP(Edin);
FCSHK; FHKAM(Surgery)
Tel (電話): (852) 2609 6870
Fax (傳真): (852) 2603 6958
E-mail (電郵): sydneychung@cuhk.edu.hk

副院長
霍泰輝教授
Associate Dean
Professor T.F. Fok
MBBS; MD; DCH; FRCP(Edin);
FHKAM(Paediatrics); FHKCPaed; FRCPCH
Tel (電話): (852) 2632 2850
Fax (傳真): (852) 2648 9134
E-mail (電郵): taifaifok@cuhk.edu.hk

助理院長（臨床期科學）
張明仁教授
Sub-Dean (Clinical)
Professor Allan M.Z. Chang
MBBS; PhD; FRACOG; FRCOG; FHKCOG;
FHKAM(Obstetrics & Gynaecology)
Tel (電話): (852) 2632 2806
Fax (傳真): (852) 2636 0008
E-mail (電郵): mangzchang@cuhk.edu.hk

助理院長（醫學教育）
鄭振耀教授
Sub-Dean (Medical Education)
Professor Jack C.Y. Cheng
MBBS; MD; FRCS(Edin & Glasg);
FRCS(Edin)(Orth.); FACS;
FHKAM(Orthopaedic Surgery);
FHKCOS; FCSHK
Tel (電話): (852) 2632 2727
Fax (傳真): (852) 2637 7889
E-mail (電郵): jackcheng@cuhk.edu.hk

助理院長（臨床前期科學）
李卓子教授
Sub-Dean (Pre-Clinical)
Professor C.Y. Lee
BSc; MSc; PhD
Tel (電話): (852) 2609 6876
Fax (傳真): (852) 2603 5382
E-mail (電郵): cheukyulee@cuhk.edu.hk

策劃處處長
陳燿墉先生
Planning Officer
Mr. Andrew Y.Y. Chan
BA; CertEdMgt
Tel (電話): (852) 2609 6788
Fax (傳真): (852) 2603 6958
E-mail (電郵): yungchan@cuhk.edu.hk

APPENDIX 13 **Correlations between socio-demographic characteristics and psychosocial outcome measures at baseline**

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Family carers																					
1 Age	1.00	0.12	0.08	0.12	0.06	0.04	0.09	0.01	0.05	0.02	0.03	0.18	0.09	0.12	0.08	0.09	0.14	0.07	0.09	0.11	0.04
2 Education level		1.00	0.09	0.20	0.02	0.06	0.07	0.04	0.04	0.03	0.04	-0.12	0.05	0.15	0.10	0.11	0.11	0.05	0.10	-0.13	0.10
3 Relationship with patient			1.00	0.08	0.13	0.07	0.03	0.05	0.06	0.05	0.02	0.08	0.02	0.09	0.06	0.05	0.09	0.08	0.07	0.16	0.08
4 Monthly household income				1.00	0.14	0.03	0.02	0.09	0.02	0.07	0.06	-0.20	0.09	0.14	0.13	0.10	0.05	0.18	-0.11	-0.15	0.04
5 Average contact hours/day					1.00	0.10	0.07	-0.13	0.11	0.09	0.03	0.18	0.12	0.03	0.07	0.17	0.19	-0.15	-0.17	0.18	0.11
Patients																					
6 Age						1.00	0.10	0.12	0.10	0.04	0.03	0.15	0.12	0.11	0.15	0.04	0.07	0.17	0.16	0.08	0.12
7 Education level							1.00	0.05	0.08	0.06	0.03	0.04	0.08	0.10	0.07	0.04	0.10	0.22	-0.18	0.14	0.11
8 Mental state								1.00	0.11	0.18	-0.48[b]	-0.20	0.17	-0.25[a]	-0.10	0.05	0.11	0.21	-0.24[a]	-0.21	0.52[b]
9 Duration of illness	1.00	0.02	0.07	0.18	0.05	0.14	0.12	0.08	0.16	0.27[a]	0.11	0.17	0.10								
10 No. of family members living with patient		1.00	0.03	0.09	0.10	0.17	0.10	0.19	0.20	0.14	0.14	0.20	-0.15								
11 Dosage of medication			1.00	0.14	0.13	0.18	-0.16	0.10	0.11	-0.20	-0.26[a]	0.09	0.44[b]								
Outcome measures																					
12 FBIS				1.00	-0.68[d]	0.01	0.04	-0.66[d]	-0.69[d]	-0.87[e]	0.03	-0.34[a]	0.16								
13 FAD					1.00	0.04	0.09	0.44[d]	0.51[d]	0.72[d]	-0.06	0.30[a]	-0.15								
14 FSSI– services in need						1.00	0.28[c]	0.15	0.10	0.07	0.07	0.11	0.13								
15 FSSI– services receiving							1.00	-0.03	-0.06	0.06	0.10	0.25[c]	0.12								

16	SSQ6– no. of supporter	1.00	0.85[e]	0.58[d]	0.07	0.02	-0.18
17	SSQ6– support satisfaction		1.00	0.64[d]	0.05	0.02	-0.14
18	SLOF			1.00	-0.07	0.21	-0.17
19	Re-hospitalisation				1.00	0.06	-0.18
20	No. of family conflicts					1.00	0.12
21	BPRS						1.00

Note: BPRS: Brief Psychiatric Rating Scale; FBIS: Family Burden Interview Schedule; FAD: Family Assessment Device; FSSI: Family Support Service Index; SLOF: Specific Level of Functioning scale; SSQ6: Six-item Social Support Questionnaire.
[a] : $p < 0.05$, [b] : $p < 0.005$, Spearman's r_s; [c] : $p < 0.05$, [d] : $p < 0.0005$ and [e] : $p < 0.0001$, Pearson's r.

APPENDIX 14 ESTIMATED MARGINAL MEANS, STANDARD ERRORS AND 95% CONFIDENCE INTERVALS OF OUTCOME MEASURES AT BASELINE AND POST-TESTS

Measures		Baseline			Post-test 1			Post-test 2			Post-test 3		
		M	SE	95%CI	M	SE	95%CI	M	SE	95%CI	M	SE	95%CI
FBIS	MS	21.61	1.07	19.47-23.74	18.66	0.82	17.02-20.29	17.11	0.91	15.29-18.92	15.87	0.82	14.23-17.51
	SC	22.21	1.07	20.08-24.35	25.71	0.82	24.08-27.34	24.34	0.91	22.52-26.16	25.45	0.82	23.81-27.08
FAD	MS	16.19	0.17	15.76-16.42	17.86	0.18	17.38-18.11	20.34	0.22	19.76-20.63	21.52	0.18	20.98-21.69
	SC	16.18	0.17	15.82-16.49	15.57	0.18	15.10-15.82	14.61	0.22	14.04-14.90	14.29	0.18	13.75-14.46
FSSI													
Services in need	MS	6.84	0.27	6.30-7.39	6.08	0.20	5.67-6.49	5.00	0.16	4.69-5.31	4.82	0.17	4.49-5.15
	SC	6.31	0.27	5.77-6.87	7.71	0.20	7.31-8.12	7.53	0.16	7.22-7.84	6.58	0.17	6.25-6.91
*Services receiv*ing	MS	4.32	0.20	3.91-4.72	4.47	0.19	4.10-4.85	4.53	0.13	4.27-4.79	4.40	0.15	4.10-4.69
	SC	4.03	0.20	3.62-4.43	5.16	0.19	4.79-5.53	4.95	0.13	4.69-5.21	4.00	0.15	3.70-4.30
SSQ6													
No. of support	MS	2.95	0.16	2.71-3.19	3.10	0.25	2.80-3.41	3.64	0.21	3.28-3.98	4.32	0.20	4.01-4.68
person	SC	3.00	0.16	2.83-3.18	2.91	0.25	2.68-3.23	2.60	0.21	2.26-2.93	2.68	0.20	2.35-2.90
	MS	2.96	0.21	2.80-3.14	3.36	0.18	3.16-3.52	3.80	0.54	3.56-4.08	4.04	0.61	3.80-4.24
Level of satisfaction	SC	3.05	0.21	2.82-3.21	2.65	0.18	2.42-2.84	2.13	0.54	1.98-2.38	2.12	0.61	1.96-2.40
SLOF	MS	150.16	1.39	145.50-151.03	161.02	1.67	158.31-164.96	172.10	1.43	167.14-172.86	176.85	1.36	171.87-177.29
	SC	148.84	1.39	144.18-149.71	144.39	1.67	141.68-148.32	139.42	1.43	134.46-140.17	135.90	1.36	130.92-136.34
Re-hospitalisation	MS	8.28	1.08	5.95-10.26	6.64	0.86	2.70-6.14	5.73	0.99	1.61-5.55	4.76	1.01	0.52-4.53
(days/month)	SC	8.73	1.08	6.40-10.71	9.77	0.86	7.84-11.27	11.47	0.99	9.34-13.29	12.79	1.01	10.55-14.56
Number of family	MS	6.56	0.32	5.88-7.16	6.21	0.27	5.54-6.60	4.97	0.22	4.43-5.32	4.25	0.23	3.74-4.65
conflicts per month	SC	6.22	0.32	5.54-6.82	6.61	0.27	5.94-7.00	7.75	0.22	7.21-8.10	7.92	0.23	7.41-8.32
BPRS	MS	25.69	0.57	23.13-28.24	26.00	0.49	24.64-28.23	24.83	0.42	22.97-26.72	24.90	0.49	22.70-27.10
	SC	25.58	0.57	24.52-26.64	26.00	0.49	25.08-26.92	25.45	0.42	24.67-26.22	25.55	0.49	24.64-26.47

Note: MS: Mutual support group; SC: Standard care group.
M: Adjusted mean; SE: Standard error; 95%CI: 95% confidence level.
BPRS: Brief Psychiatric Rating Scale; FBIS: Family Burden Interview Schedule; FAD: Family Assessment Device; FSSI: Family Support Service Index; SLOF: Specific Level of Functioning scale; SSQ6: Six-item Social Support Questionnaire.

APPENDIX 15 CHARACTERISTICS AND COMPARISON RESULTS OF THE MUTUAL SUPPORT SUBGROUPS

Table: Socio-demographic characteristics of family carers and patients in 3 subgroups

Characteristics	Group A (n = 13)		Group B (n = 13)		Group C (N = 12)		Total (n = 38)	
	f	%	f	%	f	%	f	%
Gender								
Male	6	46.2	6	46.2	5	41.7	17	44.7
Female	7	53.8	7	53.8	7	58.3	21	55.3
Age	M=25.0, SD=6.1		M=26.3, SD=5.8		M=25.7, SD=5.0		M=26.1, SD=7.3	
19-24	6	46.2	6	46.2	7	58.4	19	50.0
25-30	5	38.5	6	46.2	4	33.3	15	39.5
31-50	2	15.4	1	7.7	1	8.3	4	10.5
Duration of illness at baseline (years)	M =2.5, SD=1.3		M=2.7, SD=0.9		M=2.8, SD=1.0		M =2.7, SD=1.1	
Less than two	6	46.2	7	53.8	6	50.0	19	50.0
Two to three	5	38.5	4	30.8	4	33.3	13	34.2
Three to five	2	15.4	2	15.4	2	16.7	6	15.8
Education level								
Primary school or below	2	15.4	1	7.7	1	8.3	4	10.5
Secondary school	8	61.5	9	69.2	9	75.0	26	68.4
Tertiary [a]	3	23.1	3	23.1	2	16.7	8	21.1
Patient's mental condition in the past 3 months [b]								
Improved	2	15.4	3	23.1	2	16.7	7	18.4
Staying the same	8	61.5	8	61.5	7	58.3	23	60.5
Worsened/Not stable	3	23.1	2	15.4	3	25.0	8	21.1
Dosage of anti-psychotics [c]								
Low	2	15.4	1	7.7	1	8.3	4	10.5
Medium	7	53.8	8	61.5	7	58.4	22	57.9
High	4	30.8	4	30.8	4	33.3	12	31.6
Average family conflicts/ month [d]	M=6.0, SD=2.8		M=6.8, SD=2.9		M=6.4, SD=1.6		M=6.5, SD=2.2	
1 – 3	4	30.7	5	38.4	3	25.0	12	31.6
4 – 6	6	46.2	6	46.2	6	50.0	18	47.4
7 – 9	2	15.4	2	15.4	2	16.7	6	15.8
10 or above	1	7.7	0	0.0	1	8.3	2	5.3

Note: f = frequency, % = percentage, M = mean, SD = standard deviation.

[a] Tertiary level of education refers to studies completed in university and other postgraduate studies in Hong Kong.

[b] Family carers' rating of patients' mental condition during the past three months when compared with the whole year.

[c] Dosage level of neuroleptics were compared with the average dosage of medication taken by patients in haloperidol equivalent mean values in mg/day, as recommended by American Psychiatric Association (Bezchlibnyk-Butler & Jeffries, 1998).

[d] Average values per month of family carers' self-report of number of conflicts between patients and family members in last six months.

Table: Means and standard deviations of outcome measures of three subgroups at baseline and post-tests

Measures		Baseline		Post-test 1		Post-test 2		Post-test 3	
		M	SD	M	SD	M	SD	M	SD
FBIS	Gp A	21.68	2.44	18.69	3.62	17.09	3.53	15.82	3.10
	Gp B	21.75	2.32	18.72	3.58	17.21	3.82	15.90	3.39
	Gp C	21.51	2.40	18.56	4.38	17.06	3.32	15.78	2.98
FAD	Gp A	16.07	1.07	17.69	1.14	20.10	1.48	21.31	1.18
	Gp B	16.13	1.03	17.81	1.28	20.30	1.50	21.40	1.16
	Gp C	16.05	0.83	17.71	1.00	19.98	1.22	21.29	1.25
FSSI									
Services in need	Gp A	6.86	1.50	6.09	0.99	5.04	0.58	4.80	0.90
	Gp B	6.90	1.21	6.11	1.00	5.10	0.82	4.86	1.06
	Gp C	6.80	1.12	6.06	0.92	4.98	0.70	4.78	0.82
*Services receiv*ing	Gp A	4.31	1.30	4.48	1.45	4.54	0.52	4.38	1.20
	Gp B	4.33	1.18	4.54	1.30	4.58	0.70	4.42	0.88
	Gp C	4.30	1.40	4.45	1.18	4.50	0.62	4.38	0.98
SSQ6									
No. of support	Gp A	2.96	0.86	3.22	0.68	3.70	0.68	4.25	0.62
persons	Gp B	3.00	0.76	3.31	0.69	3.81	0.80	4.31	0.89
	Gp C	3.00	0.52	3.30	0.53	3.80	0.92	4.29	0.70
Support satisfaction	Gp A	3.04	0.60	3.32	0.61	3.72	0.60	4.22	0.67
	Gp B	3.08	0.74	3.38	0.72	3.80	0.70	4.28	0.82
	Gp C	3.06	0.68	3.35	0.60	3.75	0.60	4.25	0.64
SLOF	Gp A	148.01	8.99	161.41	9.22	169.90	6.72	174.38	7.60
	Gp B	148.76	8.98	161.80	10.02	170.34	10.33	174.82	9.02
	Gp C	148.48	9.12	161.65	9.97	170.02	9.02	174.61	8.15
Re-hospitalisation	Gp A	8.10	7.02	6.62	3.50	5.50	5.33	4.51	3.90
(days/month)	Gp B	8.23	6.20	6.52	4.04	5.63	5.21	4.58	3.82
	Gp C	8.08	6.01	6.40	3.19	5.51	4.98	4.49	3.98
Average amount of	Gp A	6.53	2.06	6.08	1.60	4.85	1.16	4.18	1.44
family conflicts per	Gp B	6.55	2.10	6.10	1.71	4.91	1.31	4.23	1.50
month	Gp C	6.50	2.31	6.05	1.58	4.83	1.23	4.20	1.40
BPRS	Gp A	25.65	2.26	25.98	2.10	24.82	1.76	24.87	2.10
	Gp B	25.70	2.31	26.05	2.19	24.87	1.83	24.94	2.21
	Gp C	25.69	2.08	26.01	2.36	24.83	1.74	24.86	2.08

Note: Gp A, Gp B and Gp C: 3 subgroups (A, B & C) of the mutual support group in this study.
BPRS: Brief Psychiatric Rating Scale; FBIS: Family Burden Interview Schedule; FAD: Family Assessment Device; FSSI: Family Support Service Index; SLOF: Specific Level of Functioning scale; SSQ6: Six-item Social Support Questionnaire.

APPENDIX 16 SAMPLE INTERVIEW DATA TO ILLUSTRATE THE THEMES THAT EMERGED FROM THE CONTENT ANALYSIS

Theme/sub-theme	Verbatim illustrated the ideas under the specific theme and sub-theme
7.3.1 Personal changes in identity, perception and coping behaviour	
Changes in personal identity in relation to caregiving	"I recognised that my previous thoughts about my relationships with patient, family members and other people were not correct and appropriate. In the past, I always blamed myself about any inadequate care provided to my child or any family problems, fault, or medical history leading to my child's illness. After participation in this group, I recognised that all these reasons were not important to me, and the most important thing is to accept the responsibility and perform the primary caregiving role in my family… Similar to other caregivers in the group, I have also taken up this role and I could find from their sharing that they have taken up this caregiving role happily and satisfactorily." (Interview, Carer 11, para. 34) [a] "I don't mind being labelled as "mad" or "family with insanity or disability". I dare to tell others what happened to my husband and my family. I would not ask 'why me?' but I would tell myself 'I should try my best to help my husband's recovery and take care of other family members, because they are my family members. I got support from others with similar situation … and problems." (Interview, Carer 19, para. 62) [b] "Despite the differences between me and my sister, I like her. She is my dear sibling and the distance in our relationship is caused by my lack of commitment and passion, but not the problem illness behaviour of my sister. I avoided facing with the illness because I did not want to take up the role of a family carer of a mentally ill and think about the stigma from friends and neighbours. All these are not so important to me because, when I opened myself to others, I have got a lot of understanding and support from my relatives and friends in caring for my sister." (Fourth group session, Carer 16, para. 81) [a] "Although my son has been very unstable in mental state in the past few months, I can be able to take care of him with more satisfaction. Even though other family members do not accept my son's illness, I can feel more positive about the relationship with my son and his behaviour and future life. I do not feel frustrated and guilty about the illness, and the other hand, I can see my importance in the care of my child." (Interview, Carer 10, para. 39) [c]

[a] verbatim quoted from the group discussion or interview of the family carers with significant improvements in psychosocial outcomes one week after the mutual support group intervention.

[b] verbatim quoted from the group discussion or interview of those carers with mild or no improvement in psychosocial outcomes one week after the intervention.

[c] verbatim quoted from the group discussion or interview of those carers with deterioration in psychosocial outcomes one week after the intervention.

Changes in perception of mental illness	"I didn't understand what schizophrenia or other mental illness was before participation in this support group. I heard a few words of explanation by our psychiatrists in the hospital and the clinic… the psychiatrist in the clinic told me that this illness was a serious problem of my son's mind and behaviour. There were a lot of factors influencing my son's onset of the illness. I did not understand clearly those factors and their meaning in applying to my son's condition… I heard that schizophrenia could be related to family inheritance or relationship. This made me feel very distressed and guilty because my son's illness might be caused by my poor and inadequate efforts of family care… or our genetic inheritance… these bring along a lot of unhappiness, concerns and self-blaming. Nevertheless, the support group helped me better understand the illness, its causation and symptoms, treatment and prognosis. I don't put the full responsibility of the occurrence of my son's illness onto my shoulder or my family. There are a number of possible factors… but the causes of the illness may not be known or fully understood. Therefore, as my group mates told me in the support group, the most important thing I need to do is to know how to take best care of my son and assist and accompany him to undergo most psychiatric rehabilitation and recovery." (Interview, Carer 19, para. 77) [a] "Before participation in the support group, mental illness or schizophrenia to me is a mystery or an unknown subject. I am now having better understanding of the causes, major symptoms, disturbing behaviour, treatment, medication, etc. I also understand the needs of my ill relative (elder sister) and why he presented some strange and problem behaviour. I can accept this behaviour is not what my relative would like to do… but he can't control over these symptoms. My relative really felt being much disturbed by the voices (auditory hallucination) from his mind and their instructions and comments on his actions and thought. I learned from the group that I could explain these false perceptions to my relative and encourage her to control or ignore the voices. After a few times of practice, I can help my relative to sometimes relieve her disturbance caused by the symptoms." (Tenth group session, Carer 7, para. 39) [b] "The group did help me change the perception of the illness… I understand that it is possible for me at least to help my wife control over some of her illness symptoms and thus reduce the family's psychological tension caused by the behavioural disturbances resulting from these symptoms. The group can also help me to recognise my role and responsibility of caregiving, from the discussion among the carers with similar situation, but not drill the feelings of guilt and blame concerning the illness into my family." (Interview, Carer 3, para. 68) [b]

[a] verbatim quoted from the group discussion or interview of the family carers with significant improvements in psychosocial outcomes one week after the mutual support group intervention.

[b] verbatim quoted from the group discussion or interview of those carers with mild or no improvement in psychosocial outcomes one week after the intervention.

[c] verbatim quoted from the group discussion or interview of those carers with deterioration in psychosocial outcomes one week after the intervention.

Adoption of new role and coping skills for caregiving	"I was convinced that... all the coping and patient management methods suggested by the group had... realistic and positive effect for most of us. I attempted to use some of these strategies, which appeared to be very useful to me. I really liked the sessions on how caregivers maintained hope and took care of themselves and appreciated the strategies suggested by other caregivers, and I think I have found a few possible answers for my particular case." (Fifth group session, Carer 15, para. 29) [a] "In the past, I felt this caregiving was a troublesome and heavy task, but now I found this can be an enjoyable experience. My husband (patient) liked to talk with me about his problems and concerns and I told him what I think and can work with him. I think he really treats me as his partner in helping his recovery, but not his burden or trouble maker." (Caregiver 19, para. 58) [b] "It is very difficult to learn how to care take of my sister, who always quarrelled with me even over trivial things. I listened about some successful caregiving experiences in the group, but I was only able to apply some in my family life. My sister's mental condition might be the worst in the group. She had hallucination and delusion... she didn't like to talk with others... Frankly speaking, the group did help me assist my sister to make more contact with me and parents and improve her hygiene and self care over this six months period. I understand that I may need more technique... and patience for assisting her psychosocial functioning and behaviour ... I am still looking for an answer for my own situation."(Interview, Carer 14, para. 30) [c]
7.3.2 Positive and negative group characteristics	
Group ideology and consensus	"I think we (group members) did well to keep our objectives of the group and each of its sessions to the simplest and achievable. We could have enough time to complete the planned activities and discussion one by one without much hurry. The group members and I had kept in mind that we only wished to change our ways of living with our family and take care of our sick relative effectively. We did not intend to learn how to cure the relative, but at least we could remove our feelings of helplessness and try to rebuild a more healthy living... happier and harmonious life... with our family as well as our ill relative." (Ninth group session, Carer 15, para. 70) [c]
	"At the first two group sessions, I was not sure the usefulness of this group to me and I did not know what I can tell others. But later on, I found that I could catch up with the other group mates and understand the common goals of the group. Every session, we had a few targets to be achieved and this was useful to me to know what should be going one in the group and we could share my feelings and opinions according to the explicit objectives restated in the start of each meeting. Although sometimes I did not get used to too openly discuss and challenge others' ideas, decision and actions, I still could accept the group participation because the group atmosphere was good and... friendly and... I felt we did have some honest discussion with respect and true mutual concern and comfort. I really enjoyed being in the group and gradually learned to resolve my family problems stemming from patient problems and care. I had written down the targets (objectives) in each session and thought about them one by one when I was not occupied with household chores at home... Most of us in the group learned to think positively about our role in the family at that time and in the future." (Interview, Carer 10, para. 66) [a]

[a] verbatim quoted from the group discussion or interview of the family carers with significant improvements in psychosocial outcomes one week after the mutual support group intervention.

[b] verbatim quoted from the group discussion or interview of those carers with mild or no improvement in psychosocial outcomes one week after the intervention.

[c] verbatim quoted from the group discussion or interview of those carers with deterioration in psychosocial outcomes one week after the intervention.

Relational social climate - Group cohesiveness	"I enjoyed the sense of unity and coherence among our group mates by showing our commitment to the group activities and maintaining the friendship for one another through different within and outside-group interactions and contacts. This friendship was very precious to me as similar to my family members. Two group mates, who are my very best friends in the group, often assisted my family to settle the household chores such as cleansing, decorations and other housework, especially when my relative's mental condition was very poor and demanded a lot of time to take care of his daily life. I feel very impressive and touching by their wholehearted assistance and support. Therefore, I also offered help to them when they needed. We formed some close bonding and intimate relationships between the group members, and each of us got at least two or three close friends within the group, who could seek help and support outside group meetings. This mutual helping relationship could not be found from relatives and other friends." (Interview, Carer, 10, para. 89) [a] "Although I could not attend the group a few times, I like to join the group discussion and activities… sometimes outside the group meeting time and we could have a few close friends (group mates) together and talk about our family affairs and events. Our linkage did not only restrict to the two-hour periods of the group sessions, we had a lot of contacts via phone, social activities and home visits. I think all these contacts and activities are very important to build our relationship and understanding of each other's needs and concerns. That's why even I missed a very few sessions, I could still know what happened in the group and could join in the discussion and activities any time without any unfamiliar or uncomfortable feelings. I think the close bonding between the group mates together with the outside group contacts did help me and other members maintain a good relationship and a sense of cohesiveness within the group." (Interview, Carer 2, para. 40) [b]
Relational social climate - Task (goal) orientation	"I feel our group was well structured and systematic with themes in each session, and was good to have much opportunities to discuss about our actual 'real life' problems. I could learn how to manage my relative with mental illness. I can remember a variety of methods had been suggested by the group-mates to improve my relative's drug compliance. I had never thought about these before, and some of them were effective to my practical use." (Interview, Carer 8, para. 55) [a] "Our group was conducted smoothly in a well organised manner. We focused on our main goal – share with other members and mutual learn and support on coping with our caregiving role. The facilitator and most of the group members did emphasise this common goal during each group meeting. With this common goal, we could plan our activities and discussion to achieve it and our group would then not deviate from our main concern. I think this is important to me and other members because we did not have much time to meet and discuss all our problems in the 12 group sessions. If we needed to meet every member's concern about their caregiving and family life, we would have to be more focusing on a few major problems from each family carer in the group. At least everybody could raise their own main concerns, which were thoroughly discussed and considered during the group meetings. I think we have done this very well and most of us, at least me, feel satisfied with this goal-focused group activities. What had not been done in the group session could be made up in some extra group contacts and activities initiated by different close participants." (11th group session, Carer 9, para. 29) [b]

[a] verbatim quoted from the group discussion or interview of the family carers with significant improvements in psychosocial outcomes one week after the mutual support group intervention.

[b] verbatim quoted from the group discussion or interview of those carers with mild or no improvement in psychosocial outcomes one week after the intervention.

[c] verbatim quoted from the group discussion or interview of those carers with deterioration in psychosocial outcomes one week after the intervention.

Relational social climate - Openness in discussion	"When I thought about the group meetings and reflected what I had done in the group, I recognised that I had gained a lot from the group and this might be related to my willingness to openly disclose my problems… in my family… and sharing my opinions with other members. I can see some of the group members like me could live happier and more healthy in family life… less conflicts with patient and other family members, more accepting to their role and responsibility of family caregiving, and most importantly, had better psychological well-being… more smiles wearing on their faces, similar to mine. I can tell you if we could not open ourselves to share our feelings and problems in the support group, we should not have been in such comfortable and optimistic attitude towards our patient's illness and our future life. The group was the most appropriate venue… and the best opportunity to talk about our worry and concern… release of our stress and sadness about those difficult and unresolved family problems… I am not saying that the group participation can solve all these problems but it can help to rethink and reconsider about their alternative solutions or sometimes their acceptance… letting them go or letting it be … could be a means of settling our feeling and distress, however, with some important psychological support and assistance from our group members." (10th group session, Carer 12, para. 55) [a] "I agree that opening ourselves in the group discussion is very much important to be involved in the group and get more benefits from the group participation. I could find some of us did attend the group regularly and actively participate in the discussions in most of the sessions. They had shown great changes in terms of their views of patient care and acceptance of the mental illness and their family life. They could tell others what they thought and felt about their family members and their patient. They could also admit their faults and on other hand recognise their success on patient and family care. Although I could not do as similar to what these active members did, I understood that I needed to be more initiative in telling others what I needed or worried about… I have improved a bit through the group participation and I can be more willing to talk with my group mates, family members and friends and tell them what I want, or I can sometimes request for their help if needed." (Interview, Carer 15, para. 48) [c]
Informational support and feeling of empowerment	"Giving me some useful information about patient illness and care was the most important component of the support group and I think this should be one of the purposes of organising the support group for us. After I had understood more about the illness and its treatment, especially the use of medication and its effects, I felt less uncomfortable and more certain and clear about my daughter's illness and her treatment plan. As the other family carers in the group, I can better control over the management of patient's problem and disturbed behaviour and I can understand her psychological needs such as needing someone to show empathy and talk to her when she felt very annoyed by the hallucinations or other psychiatric symptoms. I can complain about these to me and I can listen to her patiently. The knowledge and skills learned in the support group helped me handle many family problems in relation to patient care. I feel more confident and resourceful in managing the family situation and care. I also heard about these benefits form other group members during the latter group sessions." (Interview, Carer 20, para. 81) [a] "I think most helpful to me in the group participation is to obtain a lot of useful information about schizophrenia and how it affected my relative … and also how to take care of him. My group was very keen to enhance our ability and competence of coping with caring for the patient with such mental illness … that is our main concern … making us feel distress and thus being the reason of our participation in the group." (Interview, Carer 2, para. 55) [a]

[a] verbatim quoted from the group discussion or interview of the family carers with significant improvements in psychosocial outcomes one week after the mutual support group intervention.

[b] verbatim quoted from the group discussion or interview of those carers with mild or no improvement in psychosocial outcomes one week after the intervention.

[c] verbatim quoted from the group discussion or interview of those carers with deterioration in psychosocial outcomes one week after the intervention.

Inhibitory factors influencing group development - Irregular or low group attendance	"I don't like to see somebody absented in the meetings. I think this absence or irregular attendance might affect the group functions and activities. At least, we had to brief them about what had been discussed or achieved in the previous session(s). The absentees always told the other members that they were not clear about what they were responsible to or refused to do some tasks agreed by the group… sometimes they did not want to talk with us about their family events. This may indicate that they were not familiar with the group norms and did not understand the importance of mutual sharing in the group sessions. Mutual support and close bonding can only be formed if we meet regularly and understand our common goals and needs." (Eighth group session, Carer 3, para. 48) [a] "I did not attend the group regularly and I knew that this would affect my gaining from the group… and this also reduce the group cohesiveness and relationship between the members. I did not want to be absent but I lacked time to attend all of the 12 group sessions because I was the only one taking care of the patient and no available place or person to temporarily leave the patient there. However, if another support group is run again, I can better arrange my time and caregiving and attend the group. Nevertheless, despite I attended the group only four to five times I could gain some benefits from the group participation… I learned some ways of coping with my caregiving from similar experiences of my group mates. I have to send my apology to other group members for their patience on my absence and allowing me to stay inside the group to the final end of the programme." (Interview, Carer 14, para. 79) [c]
Inhibitory factors influencing group development - Negative and high peer pressure and dominance in group	"I felt a lot of pressure from one of the experienced carers in the group. She always instructed me to share my views about the discussion topics. After I gave my personal ideas and ways of family care… particularly those she found not preferable, she would speak loudly and scolded me in front of other group members. She went on giving a lot of negative remarks to me and another group mates until some members who closely related and very supportive to me stopped her doing this impolite behaviour to us. Our group facilitator had talked to her about her subjective bias and hostile behaviour to other group members. She sometimes dominated the group discussion and some timid and passive members did not have chance to talk about their family situation. It appeared that after a few group sessions she showed more polite and patient to us and let others talk freely about their family events. From time to time, when she indicated being irritated by our undesirable caregiving behaviour, the facilitator or a few experienced carers would divert her attention to other issues or accompany her out of the group to have a time break and calming down." (Interview, Carer 18, para. 69) [b]

[a] verbatim quoted from the group discussion or interview of the family carers with significant improvements in psychosocial outcomes one week after the mutual support group intervention.
[b] verbatim quoted from the group discussion or interview of those carers with mild or no improvement in psychosocial outcomes one week after the intervention.
[c] verbatim quoted from the group discussion or interview of those carers with deterioration in psychosocial outcomes one week after the intervention.

- Negative and high peer pressure and dominance in group (cont'd)	"The most important factor influencing the group development or individual benefits from the group is the negative remarks and actions of two dominant members to the other group mates. These dominant members were very experienced carers and they could tell us a lot about their caregiving experiences and means of handling patient problems. However, they gave us too much pressure on our caregiving behaviour to the sick relative and our family care. Sometimes, they instructed us to follow their methods of patient management because they asserted their methods were the best option of patient care… they attempted each of them and from their experiences they were feasible and effective. I don't think their methods were always the best one… these methods might be the best for them but not good to me. Some of our group members showed their intent to quit the group but the facilitator asked them to stay and explain to them that the group would discuss and deal with this important problem in the next group meeting. Our group spent one hour of discussion about the dominant behaviour and their pressure put onto other group members and they agreed to change their subjective interpretation to others' needs and also not to coerce compliance of the rest of the group to their caregiving methods." (Interview, Carer 19, para. 38) [b]
Inhibitory factors influencing group development - Over-expression of intense negative emotions	"I was afraid of encountering the group members' intense emotional reactions toward others' difficult and undesirable family situation… I also felt sad and sympathy to the unfavourable situation but I can keep myself detached from the thrilling experience and thus less intense negative emotions. We had a few times that one of the family carers expressed very sad and irritable family events during group meeting and she cried out loudly and the other group members had difficulty in making her settled from her negative emotions. I also experienced once that one father carer was very angry when talking about his patient's behaviour and great disturbance to the family life. When another male member asked him to calm down and the father showed very agitated and hostile to the male member. The facilitator immediately announced a time break and separated them for individual discussion and settled their intense emotional reactions to each other, as well as the said event. These situations did cause interferences to the group and might have some negative effects on the friendship between the group members." (Interview, Carer 6, para. 50) [c] "Our group had a few times of conflicts between the group members. I also involved in one of these incidents. I think conflicts cannot be avoided in a group… more importantly we need to know how to handle the conflict when it comes. After I had had a conflict with the group member about the attitude towards patient's illness, I felt our relationship was not so good as before the incident and the group mate did not talk to me about two weeks… Up to now, I still think that I did not say anything threatening or negative to my group mate. I only told him what I think and my different method of handling the situation. Other group members also expressed their opinions but the group mate felt that I did not show respect and consideration to him. He has not yet allowed me to clarify about this misunderstanding of my views and attitude to the situation. I felt regret about this and I think I should seek advice from our group facilitator to resolve the conflict but I didn't do it." (Interview, Carer 1, para. 81) [b]

[a] verbatim quoted from the group discussion or interview of the family carers with significant improvements in psychosocial outcomes one week after the mutual support group intervention.

[b] verbatim quoted from the group discussion or interview of those carers with mild or no improvement in psychosocial outcomes one week after the intervention.

[c] verbatim quoted from the group discussion or interview of those carers with deterioration in psychosocial outcomes one week after the intervention.

7.3.3 Effects of group structure and external environment	
Non-hierarchical and autonomous structure	"We were in a family group with mutual supportive nature and the group facilitator was only taking an auxiliary role. When we got something unclear and confused, we would sometimes asked for help from the facilitator, who was considered to be our resource person at those moments… The continuation of the group depended on our perceived worthiness of attending the group, mainly in relation to the level of mutual support we ourselves perceived and in consistent with what this group was named. It was equally important that there was not any power struggle among the group members since all of us were interdependent and mutually beneficial to each other… The main duties and responsibilities of each participant were to attend the group sessions consistently and share about their own experiences and skills in caregiving with others, and to offer practical help and emotional support to each other. With limited restriction of unequal power or status in the group, teamwork and commitment to the group were the key elements to achieve our goals regarding our effective coping with our caregiving role." (Interview, Carer 11, para. 21 & 23) [b] "… the flexible time schedule and content of the group allowed us to work on our common goals and individual concern more freely and creatively. We could discuss one important issue on caregiving or a common family situation over a period of time according to the group agreement and consensus. We can talk about a topic of our immediate concern, which might be scheduled in another session. Flexible time and content of discussion and freedom of working on any relevant issues about caregiving under group consensus are very important to suit specific needs of most of the group members… these characteristics are quite different from other education groups that I previously attended. Equal status and similar situation of the group members are also important elements of the group which can help us build interdependent and supportive relationship… and also easily understand each other's needs." (11th group session, Carer 10, para. 15) [a]
Perception of professional involvement and support	"We all agreed that extra help and support from health professionals in the outpatient clinics or referred by the facilitator was beneficial to the group participants, thus meeting our family needs… because more information and advice on caregiving, community resources, and patient's illness and treatment could be obtained from them. In addition, we also suggested that our group could invite different professions to give us a few talks about our most important topics of family care if needed. This can enrich our understanding of caregiving from different perspectives of the health professionals. We would like to have their extra support to enhance our group functioning and thus we did not feel separation from the health care system and the community resources available to us." (Interview, Carer 12, para. 47) [a] "Nurses and medical staff's support to our group is important because they can give us advice on medical and psychosocial issues such as update information about medical treatment and available psychosocial intervention for our family members and patients. We can share with them our views and methods of patient care and they can give us feedback on these methods. We can also learn from their expert experience of patient care… I think health professionals can be invited to sit in one or two sessions according to our topics of discussion. For example, psychiatrist can be asked to attend our second or fourth session relating to patient treatment and understanding of the mental illness." (Twelfth group session, Carer 17, para. 18) [b]

[a] verbatim quoted from the group discussion or interview of the family carers with significant improvements in psychosocial outcomes one week after the mutual support group intervention.

[b] verbatim quoted from the group discussion or interview of those carers with mild or no improvement in psychosocial outcomes one week after the intervention.

[c] verbatim quoted from the group discussion or interview of those carers with deterioration in psychosocial outcomes one week after the intervention.

Support from family members and people outside group	"My family members are very important people in supporting my caregiving and my participation in this support group. They can listen to my feelings and difficulties encountered over the intervention period, and I think, there were not any other people who can provide such immediate support to me within the family. My family can work together to take care of my daughter (patient) and frequently encourage me to try what had been learned from the group on patient care… and more importantly provide assistance and support on caring for the family and patient." (Interview, Carer 2, para. 61) [b] "I understand that I can talk about my problems and concerns regarding my family and caring for my son. I think this social support and positive social relationship with these people outside the support group has added extra strengths and warmth to my family care, as well as caring for my patient's health needs." (Sixth group session, Carer 16, para. 55) [a]

[a] verbatim quoted from the group discussion or interview of the family carers with significant improvements in psychosocial outcomes one week after the mutual support group intervention.

[b] verbatim quoted from the group discussion or interview of those carers with mild or no improvement in psychosocial outcomes one week after the intervention.

[c] verbatim quoted from the group discussion or interview of those carers with deterioration in psychosocial outcomes one week after the intervention.

APPENDIX 16 A SAMPLE OF INTERVIEW SCRIPTS

Interview 3 (Interview identity code: MSG 03)

Date: 10th January 2004
Venue/time: Interview room of 'A' clinic @ 2:00 pm – 3:00 pm
Family carer: MUM
Interviewer: IN

IN001: Good afternoon, thank you for your participation in the mutual support group (MSG) and this interview. I am going to discuss with you and Mary (nickname, daughter of the family caregiver) some issues about your participation in the support group. You can tell me as much as you can and don't feel any embarrassment and difficulties in making comments, particularly negative ones, on the facilitator and the group. Your answers and information will be kept confidential and anonymous in any reports or documents. Any questions you can ask me during the interviews. Do you have any questions about the interview?

MUM002: No. I understand what you mean. I will tell me what I think and feel, as I can.

IN003: During participation in the MSG, what are the most impressive things or incidents to you? They can be good or bad things to you.

MUM004: Yes, I can still remember the first time we met. I could feel they were the ones I trusted and could talked with. They greeted me and said what they could do for others. This gave me some special feelings … warmth and concern about me.

IN005: Yes, this is one positive event to you. Any more about your feeling and experience about this meeting.

MUM006: So am I, I felt something very special … comfortable when I attended the group meeting (2nd meeting) in December. The members were very friendly, warm and willing to offer help and support … from their conversations with me, and my daughter. (Pause, for five seconds)

MUM007: I can talk about my own situation, my family's inter-relationships and environment, and my daughter's illness conditions in the second meeting onwards. Because in the first meeting, they had given me a good model of sharing, a lot of their personal experiences, positive or negative, good or bad, embarrassed or successful … and so forth. I wondered why they could disclose their personal things so much in the first encounter. Anyway, I did not feel scared or anxious about their disclosure. On the other hand, they showed me what the courage, acceptance and a secure social environment for discussion were. I remember that I did not want to talk so much in the first meeting, but I listened attentively and carefully to what they said. Listened to what are relevant to my situation. I learned a lot from that meeting.

IN008: I can hear you telling me some encouraging experience during the first meeting. Please tell me more about the rundown of the first meeting and any part of it you feel helpful in your first experience in a support group.

MUM009: I can remember the process of the first meeting was: firstly, introduction of self, family background and membership, patient illness history and duration; secondly, telling others your expectations and purposes of participation in the group; thirdly, Hm… Hm … I can't clearly recall what it is, and I think the facilitator explained to us what the support group aimed at and the overall picture of the group programme.

IN010: Yes, after the explanation, what's next?

MUM011: The facilitator asked the members to tell something more about our needs arising from the patient care provision … and something related to family situation when caring for the patient.

IN012: What did you respond to him and how about the other members?

MUM013: I said that I felt a bit distressing and depressed. I did not know how to take care of my daughter … I had not sufficient information and skills in caregiving … I did not well

prepare for such poor situation. I had my husband, aged 55 years, and my elder son, aged 39 years and not lived with us. My daughter solely depended on my husband and I for living and staying outside the hospital. My physical condition still adequately fitted for providing care to her … and of course she is my only daughter, you know … if I did not take care of her, nobody will do this. My son has his own family and his family life … not good to involve in this trouble.

IN014: Mm … yes, then did you tell the facilitator something about your daughter's condition?

MUM015: Yes, I did. I had told them my daughter's illness, 12 months duration, medications, our family situation, e.g. finance, housing, difficulties in caregiving, etc. I told all that I wanted to learn how to take care of my daughter from the group and this is the main purpose of my participation in the group. I don't want to get money and social activities … but only want to get some information and learning from your experience and teaching.

IN016: All right, what your daughter's illness condition was at that time as compared with the present condition?

MUM017: My daughter presented in a quite different picture six months ago. She was very suspicious, withdrawn, quiet and non-responsive to questions, neglecting social activities and personal care. Always stayed at her room and did not want to talk with family members. She sometimes talked to me that she was very afraid of the voices around her, which told her that she was a fool and someone might kill her to settle the hatre with her. I felt very worried about her situation.

IN018: Ha … ha. Could you manage your daughter's fearfulness and situation at that time?

MUM019: I could not do it well, if not having the advice and support from this group. They shared their similar experience with me about how to take care of their relative's symptomatic behaviours and fear of the voices and false beliefs, etc. I learned it step by step and asked the group-mates for further information if encountered any problems … or difficulties.

MARY020: Mum, I can't remember all these you have just described. I thought that the voices were so real and I sometimes took their suggestions and might think that someone was going to harm me. I felt so sorry about these behaviours and beliefs, but I could not control my mind … not to think about it. And, I did not know how to cope with the interference of these voices and false beliefs. However, I felt my mum and dad was really supporting me … to fight with these symptoms.

MUM021: Oh, my dear daughter. I understand that you were controlled by the psychiatric symptoms and now you can better control of your illness … those symptoms disappeared, and therefore, you might not remember some of the terrible things at that time … your illness condition was really bad at that time.

IN022: What did your group members help you cope with this?

MUM023: They told me a lot of methods to live with my daughter's illness and problematic behaviours. I can remember in the second meeting they shared about the ill relatives' mental conditions and bizarre behaviours and troubles created in daily life. I felt some of the descriptions were quite similar to my situations … what I encountered had been experienced by them. They explained to me and other inexperienced caregivers to deal with those difficulties … really a great trouble to us. They showed me the ways to settle the relative in a public place, such as in a restaurant, where the relative showing very agitated and disturbing to others. I felt very delighted during the meeting, because the shared experiences was liked a book, a dream or miracle, telling me the procedure or methods of handling my daughter's illness behaviours. I could listen to the details how to work step by step in getting it correctly done … settling my daughter's emotions and interferring behaviours. They also showed me the difficulties and points to be carefully considered when facing this situation again.

IN024: Were all those are successful ways to handle their relatives' behaviours?

MUM025: No, there were some failed experiences. They told me that it was not always successful in working out the strategies they planned to do. The mental illness and its symptoms are not the same in every individual and therefore some variations in symptoms and behaviour … and emotions etc. caused different reactions and feelings of the patients. They had

attempted a number of ways to manage the patients' behaviours. They had also told me sometimes they could not do anything to settle the patient's emotion and interference. They had to use the last method – taking the patient away from the place and let him/her calm down and explain to him/her what happened sooner after the problem was over.

IN026: It seems you enjoyed participation in the group because of the learning of caregiving and sharing of similar caregiving experiences. Any other things you can tell about the first few meetings of the group?

MUM026: It was a small sized group with only 12 members. Although a few of them sometimes not turning up, they and all others were very committed to the group … I don't know whether these are commitments … they attended the group punctually, helped phoning up the members for reminding us the time for next meeting, encouraging us to attend the meetings, and asking us any difficulties encountered in-between the meetings and gave me their suggestions to handle the situations. Even though I never missed any of the 12 meetings, one or two members … yes … they phoned to me one or two days before the meeting to remind me of the time … now they become my close friend! We keep in contact after the intervention and mutually support each other.

IN027: That's great. Any other things you felt good or impressive?

MUM028: Ah … yes. One of our group members is a retired female. She was so nice and helpful … she always asked us whether we needed any practical help … such as cleansing work, taking the patient to attend psychiatric follow-up, and even taking care of the patient for a day. She is wonderful and nice. She already got one relative to be cared for, but she can have time and energy to help others. She, named Conny, always shared with us her good or bad times … not feeling any embarrassment or hopelessness to the patient illness. I still have to learn about this optimism and patience.

IN029: Yes, it is good. Anything else you would like to tell me about the things impressive to you?

MUM030: Mm… you had mentioned about a few serious arguments raised during one meeting, in which you felt a bit disappointing. Do you remember this? I think it was the second meeting, wasn't it? (Pause)

MUM031: Ah, yes. I had some arguments with a few group members in the third meeting about the ways to interact with my ill relative. I said I always instructed my daughter to do things, but when she refused to follow my instructions, I scolded her and not allowed her to explain about her decision or actions. I felt very guilty each time after the scolding … then I did not what to do. The two members disagreed with my feeling at that meeting. They told me that they would not feel guilty about the instructions and persistence on requesting the patient to follow their advices … you know what they believed about the patients' dependence and indecisiveness on daily living.

IN032: Mm … ah, how did you respond to them?

MUM033: I did not feel any angry feeling … but explained to them that my daughter was not so disoriented and poor in mental condition. Thus, she could handle some simple task in daily living, and also shopping and some social activities with friends and family members. I told them that I would like to let my daughter be more independent and have some responsibility to her own living. I believed that she could do that.

IN034: Yes, you gave your daughter freedom to choose and act in her own way. Did you feel uncomfortable and frustrated about her recurrent symptoms, not having any improvement in her mental condition, or not taking medication as prescribed?

MUM035: Yes, I felt some differences in situations according to individual relative's illness condition, even though as I mentioned, most of the experiences or patient's symptoms are similar. I do accept these differences, and also our beliefs and actions. The two members kept on forcing me to follow their opinions and suggestions, but I could not accept this was the only way to deal with patients' illness behaviour. In fact, I did not feel very unhappy about this… because it is normal to have differences in opinions and beliefs. The other group members intervene with our arguments and reminded us about one of the ground rules of this group, that is, accepting each other's differences, faults, and any unpleasant feelings of caregiving, and don't force others to follow your ideas and advices;

everyone can make his/her own options of strategies of caregiving. The facilitator also did the roundup of the discussion and reinforced the rule … and not bringing any hard feelings back home. We all agreed with this when ending up the meeting.

IN036: Well, did you feel any frustration or unhappiness after the meeting?

MUM037: No, I had not thought about the arguments after leaving the meeting venue. The two members came to talk with me after the meeting and we expressed our pardon to each other … and I can see that we could meet and enjoy the meeting afterwards.

IN038: It seems a very positive experience in the group. What do you feel about the later meetings of the group?

MUM039: When I went though the later sessions of the group. I felt much familiar with each other in the group and therefore we talked openly, without any feeling of embarrassment or hesitance. I felt being accepted in the group process and I could learn from other families with similar situations and of course I could also give some of my opinions and success in caregiving to them. As the facilitator said early in the first meeting, this group was a reciprocal learning group from people in the 'same boat'.

IN040: Yes, thank you for your comments. In overall, how do you feel about the participation in the MSG?

MUM041: I think the group is good and helpful to my caring for my daughter, particularly when she was very ill and disturbing to family and friends. I got the practical help from other members in the group. They were physically and psychological supportive to my situation and my role in the family … to take care of my daughter, that is my main concern in that period of time (at the start of the MSG). At the time, I was very distressing and anxious about my life situation … I asked myself what I could do to make my life a little bit easier. I cried more than ten times … many times … for my inability to care for my daughter. I had asked other professionals to help and give me suggestions to improve this, but at last one nurse in the clinic referred this group to me.

IN042: What's your feeling when going through a few sessions of the group?

MUM043: I felt a bit relieving from the heavy burden of caregiving. I was happy to find out some people in similar situation and helped each other to go through the stressful life situation. I enjoyed attending the group very much, even though there were sometimes frustrated about the misunderstanding and arguments between the members. I cannot sure whether it is called conflicts or arguments, it should be called disagreements between people.

IN044: What's the disagreement? Can you give me an example?

MUM045: Yes, I can remember in the third session I talked about my daughter's behaviours at home. I told the group that my daughter was very slow and lazy in doing homework and I often blamed her not helping me do any work at home. When I mentioned that I once scolded her and called her to be a fool, somebody in the group felt unhappy. I understand that this was only my sudden strong emotional response when facing with too much stress at that time. But, I felt very surprised about two of the members shouted to me, and emphasized that I should not blame my daughter for her uncontrollable behaviours. They stopped me to say any of such negative words. I felt surprised because I had an idea that the members were open in discussion and the group should accept any experiences and feelings felt during the process of caregiving. I only told them the truth… and my feelings. I could not expect such sudden return of strong reactions and blaming. (Pause)
However, they then explained to me that they were very against any blaming to the relative because they had painful experience about blaming the relative for crazy and clumsy behaviours. The results of their blaming to the relative was to cause their relative leaving home and attempted suicide by cutting wrist and jumping into the sea. Thus, they said they would never say anything so bad to the relative (patient).

IN046: Ha... hm … hm. What did you feel after they had explain this to me?

MUM047: I felt more comfortable and showed my understanding to their feelings and experiences. I explained to them a few times that those negative comments to my daughter were only my emotional reactions, and I gave my apology to my daughter immediately after such negative remarks. I did not feel angry or unhappy after this argument. The other group members did intervene on the arguments. They told us about their similar experiences and

feelings and they explained to me and other tow members that this emotional reactions and negative statements to the patient could not be avoided … they said that we all are humans … with feelings, both positive and negative to things happening. It was important to take actions to compensate or solve the conflicts or settle the emotions. Think positively and from others' point of view… how the patient feel when they were ill and did something not wanted, or how you feel when you wee the patient hearing those negative words or blaming.

IN048: Yes, it seems a good experience even with some arguments. Any other negative experiences or feelings did you encounter within the group?

MUM049: Mm … mm …yes … yes. I can recall another impressive experience in the later sessions of the group, I can't remember which the session was.

IN050: It doesn't matter about the session number. What was the incident?

MUM051: Mm … yes. I can remember that one old lady in the group requested our advice and help in caring for her eldest son, aged 30 years, who was suspicious and threatened to harm his mother (the old lady). She felt very anxious and stressful … cried out when telling us the story of her son's illness and recent disturbing behaviours. The group members and the facilitators tried to settle her strong emotion and asked her to calm herself down. They reassured her of the problem can be resolved and there should be a means of problem solving. I felt very uncomfortable at that moment, because I was not confident to give any advice or comments to the old lady. However, I was asked by the peer leader to give some suggestions and this was the first time I could obtain a sense of improvement of my knowledge and skills in patient management. I told the old lady that I would consider the condition of her son, whether he was very agitated and aggressive … observed his behaviours to ascertain any risks fo violence or harm self or others, such as taking a knife to threaten harming family members or people; socially withdrawing self, not responding to questions or greeting, and hiding in a room; saying some negative things or telling you that he did not want to alive; showing very suspicious and hostile to anyone approaching him, etc. These were the behaviours of the patient that I had encountered and being shared by the group members. Do you think this knowledge is correct and adequate for this situation?

IN052: You had given very important information about the behaviours of a mentally ill patient who indicated risk of relapse or mentally unstable. What else did you say to the group?

MUM053: I said … I said to them that it was important to observe the patient's behaviours closely when you feel something wrong … the patient may be 'relapsed' from illness (recurrent symptoms of schizophrenia). I told them that I got once to encounter the recurrent auditory hallucination and suspicions of my daughter to my elder son 1 month ago. I had to ask my son not to visit us for one month and tried to take my daughter to a early follow-up in the clinic. I felt very distressed in one month's time and I had to observe closely to my daughter, days and nights, taking away all the dangerous and sharp objects … I was afraid that she would kill people … or herself … I was so scared … but I remembered some shared experiences from my group members about how to detect the early relapse signs and manage the patient in the mentally unstable condition. I had written down some means of patient management … I always bring along with my notebook … which is very useful to my learning and refreshing my knowledge about patient care. I therefore read out my notes and points that I learned from the early sessions of the group discussion. I felt the agreement and positive appraisal by other group members … more importantly is that I acquired some confidence and recognition in caregiving. After that session, I could be more open to talk about my situation, my family and my daughter's illness.

IN054: It is really good to hear this. What did the old lady react to your suggestions and the group's advices?

MUM055: I can say that it was very good … the old lady seemed very satisfied with the suggestions and stopped carrying … but appeared a little smiling on her face. She listened very attentively to the suggestions and often nodded her head and said, 'Yes, it is very similar to my situation and experience with my son.' She said that she would follow some

advices and work out the observation and management of his son. She gave sincere thanks to us at the end of the session. We had a nice ending of the meeting.

IN056: This incident sounds not negative. What make you feel so negative?

MUM056: I felt negative … because during the discussion, one of the members who was a young man, showing annoying about the old lady's too negative feelings (as the young man perceived and told us during the discussion) about her situation and hesitancies on taking in his suggestions. He shouted loudly to the old lady and told her that she needed to be assertive to the patient and confident in her caregiving. I did not fully agree with his attitude, behaviour, and ideas. He was not the old lady … who had less power, physical ability, and help from other family members. We need to be more considerate about others' difficulties and differences … the means of patient management is not feasible and appropriate in all families or situations. And, I think, patients would present different symptoms and mental conditions … needing different management strategies or techniques. Sometimes, we needs keeping on 'trial and errors' … until we find a better way for each of us to interact and live with the patient.

IN057: You seems learned all this useful materials from the group. Am I right?

MUM058: Yes, sure. I got a lot from the group participation.

IN059: Back to the incident, what's then happened about the young man?

MUM060: The group did give him pressure to change his attitude … not so subjective about the situation of the old lady. She got her ways to tackle the problem … in her own acceptable and most appropriate time pace or style. They could not coerce her to follow exactly what we did, or suggested to her. We discussed about the differences on means of caregiving among the group members … how to manage the patient … the old lady's son. We were not aimed at group consensus on any management strategies but to give more suggestions for the old lady's considerations. The facilitator and the peer leader explained to the young member about the purpose of that discussion and the importance of empathy and free choice in the group. Let the old lady choose what she wanted. If anything she did not understand or unable to decide, we would suggest her to think more details, step by step, to see which alternative is more appropriate … to try, and it is also important to find out any other professional help needed.

IN061: What did the young man say and respond to the group?

MUM062: He was so embarrassed when we expressed our disagreement with him. But, he did not show angry and frustrated… he appeared more and more accepted to our explanation. That is, our ground rule of the group… respecting others and taking into consideration of others' specific situations and feelings. We would not intrude others' values and preferences … others' usual life and practice … the same as that they don't want us to be. The young man at the end of the meeting admitted his too much subjectivity and bias to the old lady's ways of dealing with her stuffs. Anyway, he did give apology to the old lady about his rudeness and unfriendly manner.

IN063: That's very good. I can see the strong dynamic forces within the group to maintain the group harmony and cohesiveness. What do you think?

MUM064: That's true. I could also feel the constructive maintaining forces within the group … we support each other and with minimum dominance and power struggling. Although some disagreements indicated in a few occasions … mm… it is mainly positive and constructive to every member.

IN065: Yes, are you talking about some power struggling did find in the group?

MUM066: In the beginning of the group formation, some members were more experienced in the caregivng and some were elder people with much likely to show the tendency of being respected; no matter what they said or suggested should be well received and accepted by the other group members. They liked to be appraised and recognized to be the informal leader of the group with powers and some privileges … like being served for and first one to be informed whatever being suggested or discussed among the members. I understand that this occurs anywhere … in a social group … the senior people like to be more power or status or dignity. However, this was so frequently encountered or a strong sense of power struggle in our group, that the elder or senior members could be easily approached

and talked about things … to be reasonable and listen to others' explanation or suggestions.

IN067: Yes, all these experiences described aroused some feelings and concerns about the group and caregiving situations, when you attended the MSG. What do you feel about these experiences?

MUM068: I think these experiences are common in all social groups; nothing is so ideal to be always positive and pleasant when having social interactions with other people. Although all of the group members were similar in caring for a relative with severe mental illness, much of our life experiences might not be similar and with the same consequences … we are human beings with unique characteristics and personality … nobody is the same in the world. You know. (Pause)

I feel all right and actually good in the participation of this MSG. I like to attend the meetings and discuss with others about the same topics of concerns. Most importantly, I learned a lot from the group … how to take care of my daughter and how to manage my own family life. Also, I can recognize that somebody in the world shared the similar situations and problems as mine … but some were very competent to resolve problems and remained very calm and optimistic … of course some are more similar to me… not very confident in caregiving and had to learn more caregiving skills from others. Not very pleasant but still feel have hope to control my own life tasks. Am I pessimistic?

IN069: You have indicated some awareness of self and your strengths and weaknesses through the group process. You are aware that you have learned a lot from the group. Can you tell me which parts of the group meetings most and least helpful to you?

MUM070: I have learnt something there … not only some, and actually so many things that I did not expect to have … Mm ... (a short time pause).

Note: The interviewee seems a bit difficult to organize the ideas or don't know how to put the learning experience in words. Therefore, after a 10 seconds pause, she began to ask a question.

MUM071: I understand that I have learnt a lot, but from where or which I can start. Can you give me some examples that I can start to think about the helpfulness of the group meetings?

IN072: Yes, you can start with something about any acquisition about knowledge of the illness, available services, treatment and care from the professionals, etc.

MUM073: I have learnt about the drugs, its types, functions, and side effects … and how to communicate with the patient about the importance of the drugs that she was taking … (Pause for a few seconds) She have also learnt how to communicate with other fellow outpatients and nurses about the medications. I can understand what she, and other patients, were suffering … rigid limbs and involuntary movements of body parts, etc.

IN074: Ah… all right; that's what you have learned.

MUM075: Yes, she can learn all these very well. I can also communicate with her about the effects of the medications she is being taken. I found very useful to learn this information from the group and the facilitator, and also how to manage the side-effects of the anitpsychotics … blue coloured … it may be called 'Stelazine', I am not sure. I can work with my daughter to deal with the side-effects … rigidity, excessive salvation, dizziness, malaise, etc. We feel more confidence to live with these effects. The experience and information from the families were extremely useful to us … both successful and failed experiences.

IN076: Yes, besides this information, what else you find useful or helpful to you?

MUM077: Another one is the knowledge about management of my daughter's symptoms and resulting behaviours. She was very emotionally unstable and restlessness. I learned to spend time to stay with her and listened to what she concerned about. I learned from the group to let her settled in her room and encourage her to take the medication as prescribed. My group mates told me that some of the symptoms might not reside and we had to help the patient accept the disturbance of the symptoms and try to ignore them if not so disturbing. And, take the patient back to clinic for early follow-up if necessary, when we observe the patient's relapse signs. Also, tell the doctor about the progress of the patient and the severity of the symptoms … is very important too.

IN078: Well, this is good. You can learn some methods of management of your daughter's illness and symptoms. Can you tell me any experience or means of an effective management that had been learned from the group?

MUM079: Let me think about it. Mm… (pause). Yes, I once went out to a Chinese restaurant with my daughter and we had to wait for seats available at the entrance. My daughter heard some voices … and started muttering to self. The people sitting beside her felt very curious and looked very puzzled to my daughter's behaviour. I had to immediately intervene by starting to talk with my daughter and let her not pay attention to the voices. She can ignore the voices when being occupied with other stuff. Then, the other people did not further pay attention to my daughter and we continued our conversations until we got seats in the restaurant. This method was discussed in the group and some members found very useful to avoid embarrassment and stigma from people about patient's symptoms.

IN080: Yes, thank you. Mm…

MUM081: I would like to say that before attending the MSG, I really didn't know how to communicate with daughter. Besides, I didn't have patience to care with patients. I become agitated and anxious easily when I saw my daughter showing some strange and interfering behaviours, such as shouting to air, self-uttering, not responding to questions, and standing close to people when talking with them. I don't mind these behaviour because I understand these were caused by the illness. But, other people, even our relatives, do not understand her problems.

MUM082: For my daughter, the benefits of group participation were also obvious. She said she felt much better, as she knew more about the illness, treatment, caring by mother (me), and some self-management methods. She had got some fellow ex-patients in the clinic to be her friends and had some activities together in last few months. They shared with each other and had some planning to find a part-time job. I supported her to do so and also encouraged her to approach the medical social worker for further information… to help her job seeking. She found particular helpful in participating one session on knowing more about the mental illness, listen about others' experience and problems, and discuss about themselves … their similar problems in family life and their views of future life (Pause).

IN083: Yes, your daughter appears to obtain some benefits from your group participation.

MUM084: Yes, my daughter seems more mature and willing to take care of self. She is willing to take initiative in improving her behaviour, her control of symptoms and her daily living … to be more productive … and very positive to her own living and future. She is really showing very much understanding about her illness and manage some of the problems caused by the illness, such as self-muttering, suspicion to others, and withdrawal.

IN085: Thank you for sharing with me about both of your personal experience. Any other points you want to add.

MUM086: I think that's the main points.

IN087: Now, besides the information and knowledge gained from the group, please tell me any other benefits from the group participation? For example, social relationship and material support.

MUM088: Yes, as I mentioned, I had received some practical help from one member who was retired. She helped me taking care of my daughter when I was not possible to be with my daughter for one day. I felt very appreciated about her help and I could release from my caregiving and settled my own affairs. I think this is one of the important functions of a support group; it is to assist one to take care of his/her relative with schizophrenia. When someone needs relieving or practical help, the group will initiate to support and help in relieving. I don't know whether this is feasible, as Hong Kong people are so busy … but caregivers may have full time to commit to caregiving tasks … we may have expected more time to do this, together with our relative needing care. I think this MSG can serve this purpose. I also offered this help to one of our group members who was sick for a few days. Her sister needed someone to stay with her and lead her to spend the days. That patient was not very poor in mental state, and she can perform daily routine and activities

well. But she needed someone to stay with her in daytime and advise her how to plan the activities outside home.

IN089: Did you do this? What did you feel?

MUM090: Yes, I took one day and other members helped in other two days by taking turns. I enjoyed this helping activity. Because this gave me some satisfaction and understanding about other's situation … may be better than me, or may be worse than me in caregiving. We shared the experiences after the relieving duty, and we found it was a rewarding and enjoyable experience. We can have time and opportunity to help others; we can have ability to do the caregiving for others. I can understand some situations an behaviours not presented by my daughter.

IN091: Hah…hah. Did you find any emotional support and psychological comfort within the group?

MUM092: Yes, sometimes I could see its presence … but I did not do this on others … because I do not know how to do this. I used to be action oriented, less talking than doing … or helping. I like to use actions to assist others to solve problems, but not skilful to provide comfort and effective communication. My daughter also know this … she always tell me that I am not a good person to talk or share with. She would like to talk with her sister instead of me. But, when something was needed to do, she would think of me to be most appropriate person for helping. (Pause and then gave more answers)

MUM093: Yes, she likes to seek help from me about the problems in daily life … but it doesn't mean that she always wants to stay and talk with me. Sometimes, she would like to talk with me about some daily news and her mental condition… but when she needed advice or emotional support on symptoms and their management, I was not the first one for her to be approached. However, she told me that she recognised some changes on me after I participated the group… She thinks… I was able to be more sensitive to her emotions and mental condition. I could give her some words of encouragement, with soothing effect… appearing to make her calm and settled.

IN094: Well, this is also a good learning. Mum, did you receive any information about the community services and resources that were useful to you?

MUM094: Mm… mm. Yes, some of them were being used and some were not useful to me… I think I don't need much support from the existing health care services.

IN095: Then, which types of services or supporting resources do you need?

MUM096: My daughter is still follow-up in the OPD and we have consultation from the medical social worker in the clinic. They support me with the financial needs – we are in CSSA (money of public assistance). I can also bring my daughter to the social centre near our residence to have some daytime social and recreational activities, and this was referred by the social worker. I got the information from my group member living in the same district. She advised me to join some activities that were suitable for my daughter, and sometimes also me. I like that centre and the staff there. They are so friendly and supportive. They are working for the mentally ill clients. Therefore, they know our needs very much.

IN097: Yes, what other services are you using?

MUM098: We also are visited by the CPN (community psychiatric nurses). They had home visits to us every one to two months, depending on my daughter's mental condition and their time. The nurse can give us a lot of advices and information about caring for my daughter's health needs, behaviours, and symptoms. But, because of the time available, at most 45 minutes each visit in one month, we feel not enough to get help whenever necessary. We had so many questions when my daughter discharged from hospital, and we felt a bit at a loss over that period. I was glad to join the MSG just after my daughter's discharge. When the man, Mr. Yip, asked me whether I consented to participate in the group, I was excited to join it, although I really not sure whether it can help us tackle our problems. But, when I attended more than two sessions, I felt it was useful to me and my daughter, therefore I continued participating in the group until the ending session last month.

IN099: That's good. Any other services are you using?

MUM100: I have sometimes used the counselling service from the clinical psychologist whenever I felt very distressed. I had met him twice … at the time … just after Mary's discharge. But, after joining this group, I did not consult him any more … may be because I felt lesser and lesser stressful over these few months. Ah … mm… Yes, I think these are the services that I am using.

IN101: Do you feel these services are sufficient for meeting your family needs?

MUM102: Yes, quite sufficient for us. I know some of my group members used more services … to serve their complex needs … like more special allowance or financial support, day hospital for patients, frequent visits and follow-up, or even regular appointment with clinical psychologist. We luckily do not need so many services.

IN103: Besides the social services, what did you obtain from the group … how about the social relationship with other members? That means, have you got any close friends or companions with some group members?

MUM104: Yes, sure. I got a few very close friends and we always meet outside of the group meetings. They lived near to my living district. They have very similar situation in caregiving as mine and their children got mental illness for three years and now followed up in the same OPD as my daughter. Although my daughter did not know their children, they got very similar symptoms and illness condition. They are living in a public housing estate as I do. The children's age is similar and we always talk together for the ways of caring for our mentally ill child. We could think about how to tackle the common problems in the family, such as family members' relationships, social activities, caring role and difficulties in handling patient's symptoms and behaviours. We found our relationship was good, intimate and mutual supportive. Sometimes, they helped me take care of my daughter for one day when I really want a time break in caregiving … to reduce my feeling of distress. I could have some family activities with other family members and my friends. And, of course, I would take this relieving role for them if needed. The group members and the facilitator recommended this temporary relief of caregiving role during the early sessions of the MSG.

IN105: Yes, thank you. Then, I would like to know whether you got any friendship or support from the people outside the group, particularly whether there has been any increase of supporting persons after you participated the MSG.

MUM106: As the group members told me that it is very important to have some more support from other people in taking up the caregiving role, such as family members, close friends, and church fellows, etc. I felt a very good improvement in my feelings and emotions after I had sought … and obtained some additional support from other people, particularly my sister and one of my close friends. They gave a lot of psychological support to my difficulties in caregiving … when I wanted to give up … when I felt very unhappy and sad about the deterioration of Mary's mental condition a few months ago. When I felt despaired and helplessness, these people were my good cushion for support and persons for emotional ventilation … and the means of seeking immediate support. Between the two meeting dates of the MSG, I would prefer to contact these supporting persons for psychological and instrumental support … and then if I could not find them, I would contact the close friends in the MSG for assistance. It was sometimes because I though the group mates had their own difficulties and constraints in caregiving … and I did not want to interfere their time and work and add some additional burden to them. Even though, I myself did want other group members to seek help from me, I usually did not contact them for the first line support. I also felt that they would not refuse my request for help.

IN107: Do you think the support outside this group is enough for psychological and social support?

MUM108: Yes, sure. My close friend is the one I knew her for more than ten years. She had experiences in caregiving for a relative with chronic illness. She understood my concerns and needs … she always initiated the help before I asked for it … she showed empathy and love when I indicated stressful and anxious … when I cried, she held my hands and let me talk through the difficulties and emotional distress. She was so patient and kind.

My sister was also very good and supportive … she … she often came to my home and visited my family. She has a very good relationship with her niece. She liked to go out with her for shopping and outing. She was excellent and very good and supporting family members of me. I am very lucky … I think God treat me good and never put my needs aside.

IN109: Well, that's very good. During the MSG meeting, did all of you have opportunity to express your feelings and concerns; no matter they were positive or negative?

MUM110: I think … we could say and tell others about our needs and concerns. We liked to share openly with other members about our feelings and distress about the caregiving role. Although different people will have different backgrounds and their own stories, we still could understand others' concerns and attempted to help … or at least listen to others' stories.

IN111: Could you show understanding and same feeling (empathetic) about others' stories of caregiving? Would you mind sharing with me about this?

MUM112: Yes, sometimes it might be difficult to understand all of their stories … because some were not seen or experienced by me. Some experiences were quite unique and personal and therefore I could not have any comments or suggestions on them. Therefore, sometimes I did not feel adequate understanding about their difficulties because different patients have different problems … and life stories. But, I saw other group members might react very quickly about their concerns and experiences … because they encountered those similar situations. I began to understand why we needed a social group … a group rather than one helper, counsellor or partner.

IN113: Yes … mm … you have told me a lot of good things to you about the MSG. What are the negative things about participation in the group, if any?

MUM114: There were some group experiences not good to me … for participating in the group. The first one is, as I have mentioned, sometimes the group members criticized my ways of caregiving and made me very angry and embarrassed. I understand that this group is the one accepting feelings, emotional reactions … criticism ... and without any ill feelings when openly disclosing yourself. But sometimes it is very difficult for me to accept all these frustrations … all sorts of blaming or criticisms in the early stage of the group participation. I did not get used to these comments and openness in social interactions. Anyway, when I observed and listened to others, I gradually adapted this ways of communication and discussion. After each meeting, we (group members) forgot all the strong comments during the meeting and remained as friends and kept in close contact by telephone and the Internet.

IN115: Ah … this is the first negative thing. What else?

MUM116: I had one to two meetings arriving late because the scheduled dates and time might not fit with my time schedule and I had to settle my daughter at home with someone stayed with her or got her engaged in some activities in social centre. Sometimes I had to rush to the group and left immediately after the meeting to take my daughter home. However, I still enjoyed participation in the group and my daughter understood my situation … the importance of attending the group.

IN117: What do you think about the length of each meeting? Is two hours appropriate for each meeting?

MUM118: Yes, I think the 2-hour length of meeting in every two weeks was appropriate for me. I can manage attending the group over these time intervals.

IN119: Yes, any other negative effects of the group participation to you?

MUM120: Once I felt a bit disappointed about the descriptions of patient's prognosis of the illness by a few members within the second meeting. I listened carefully about what they expressed their concerns about patient's recovery and long period of rehabilitation, and so forth. They looked very sad and pessimistic and frustrated. Other group members were a bit silent and did not say too much to oppose to their ideas. In spite, some members gave them words of reassurance and support and asked them not to worry so much. I myself felt a bit unhappy; and the atmosphere indicated to me that the prognosis of patients was not always good … some of them might be difficult to recovery … or not having any

hope to get well. I did think of my daughter and compared their relatives with my daughter … I felt scared and uncomfortable to continue relating their illness condition with my loved one … I could not accept this happening if this occurred to me.

IN121: Yes, I understand your worries and concerns. Do you have such feeling now?

MUM122: No, I don't have this feeling any more. I can understand that every family and individual has his/her condition and … I understand that if we do our best to help the patients, we need not to be much concern about the results … it should be better than doing nothing … or less effort being paid. When I saw my daughter getting well and improved in mental state, I felt much happier and not to be disturbed by the bad experience of my group mates. I am not saying that I would not concern about other's situations, and I would still provide support and assistance to others who needed more help than me. I hope I can help all other families and patients of my group to get improved.

IN123: Besides these, did you experience any effects on reduction of your self-esteem or confidence in caregiving?

MUM124: I did not feel this effect. On the other hand, I felt better and better in ability and skills in caregiving. I learned more and more about the skills of effective communication with my daughter and maintenance of family and social relationships with people. I learned how to accept self and others, and the patient with mental illness.

Note: The mother spoke to me very strongly and confidently about this learning and effect. She held my hand and looked very delight with a smile.

IN125: In overall, how can you describe your feelings and condition after attending the MSG?

MUM126: I feel much better in getting along with my daughter and other family members. I could interact effectively with my group mates and their ill relatives. I feel very delighted and happy about this change. I would like to say that this MSG helped me a lot in caregiving and establishment of social relationships. For my daughter, she understood more the course of the illness, treatment and family care that I did, and I also told her about her mental illness and the ways she could do to improve my condition. She said to me that she would not be so afraid of the illness and its effects to her. She had more confidence to cope with the illness. She did express to me that she recognised my care and concerns to her… and worry about her. She felt a great love from me.

IN127: Thank you for the MUM and Mary's detail responses. MUM, will you continue to participate in the MSG or other similar groups?

MUM128: Yes, I have some discussions with other group members in my MSG abut the continuation of the group my our own effort and with some assistance from the OPD staff. The OPD allowed us using their room to conduct the group from next month onward. They are very supportive to our continuation of the group. We have ten members agreed to continue participating in the group.

IN129: This is so good. I hope you can mutually supportive and sharing in the future meets. One more thing about the group I would like to ask about your opinion,; that is, whether you feel the equipment and information provided by the group members and the facilitator adequate to you.

MUM130: Yes. I could obtain the information relevant and useful to me. They were all enough for me.

IN131: In the group, which aspects of information or discussion do you think not useful nor required?

MARY132: I think the session about how to teach the family members to care for the patient might not be useful to my family. I also suggest the detail information about the drug categories or types can be omitted, as the content is too difficult for us to understand.

IN133: Do you think the number of members will affect the effects of the group or your actively participation?

MUM134: No, I don't think so. But, what I mean is that it should not be more than 20 members, because it would be too difficult to maintain the large group size and allow everyone to talk about their concerns and experiences in two hours.

IN135: Do you think the venue and time of meeting was suitable?

MUM136: That is fine.
IN137: Do you think the facilitator is useful in the MSG?
MUM138: Sure, it is necessary to include him in the group. He can encourage and maintain the group discussion and sharing. He can also help the group members keep contact with others and encourage members to attend the group meetings regularly. When some conflicts arose, he did help the leader and other members settle the conflict … when we could not manage the conflicts and discussions well.
IN139: How about the peer leader? Can he lead the members to participate more in the MSG?
MUM140: Yes, the leader could lead us to participate more. He also help a lot in arranging the meetings and encouraging the members to attend the group … especially those who were inconsistent or irregular group participants.
IN141: Can you tell me a bit more about your perceptions of the role of the facilitator and the peer leader?
MUM142: I don't know what I should say … do you mean their work and responsibility in the group?
IN143: Yes, you can tell me something about what they had done. Did they do what you expected?
MUM144: The facilitator worked very hard to establish the group and organize the time schedule, venue, and materials … I mean equipment and environment. He did very well in gathering us all together and maintained our attendance of the group. He phoned me to remind me of the time of meetings and in the later stage, the peer leader also did this. Mr. Yip was very kind and patience to us. As I asked a lot of questions in the beginning of participation in the group, he had never refused to answer my questions … and the answers were always in full details … very clear and to the point. He had to spend half an hour each time to answer my questions in the phone. I feel very pleased about his sense of responsibility to lead the group. For the peer leader, she was an more experienced caregiver … his relative had the illness for more than two years. She liked to take the responsibility of helping the coordination work … phoned to some of the members for any message about the group, encouraged us to attend group, asked about our situation in caregiving … she also helped in … mm… (pause).
She helped to lead the discussion part … of each session. She also assigned some tasks for each of us, such as preparation of the meeting venue and equipment, reminding of meeting time, urgent message and help among the group members, schedule of sharing and role play … etc.
IN145: Do you think it is a good idea to ask a member to act as a peer leader?
MUM146: I think that it is a good idea, but the member may need some preparation or training to lead or facilitate the group. I understand the peer leader of our group was trained by the facilitator … for a few sessions … and she was interested in this work. She did better in the later stage of the group … that indicated the importance of experience in group monitoring and leadership. I felt that the facilitator could work smoothly with the informal leader. They had meetings after our group sessions. I felt satisfied with their way of leading the group... they can settle the arguments and conflicts with the assistance of other members … every time … smoothly and satisfaction. No one got hurting or felt uncomfortable to others after the meeting.
IN147: What do you suggest for improvement of the group?
MUM148: I can't think of any … the only one is their distribution of work … who does the telephone contact, who contacts which members … avoided overlapping or confusion … The peer leader can do more in leading the group discussion during group meeting. She can also do more sharing with others since she was much experienced in caregiving. The facilitator can work for the outside group communication or coordination such as with the clinic staff or other agencies for assistance. He can also collect some information for us about the care of patients with schizophrenia … the community services available and how to access these services. That is all I can tell.
IN149: All right. Thank you for your comments. Since you have learnt a lot form the group, will you share these with the other people needing this support?

MUM150: Until now, I haven't prepared for this. But, I can certainly consider this because someone had helped me a lot. I needed to give the support to others, not only to the group members.

IN151: Do you any other comments on the MSG?

MUM152: Nothing else. The knowledge about the illness and management of patient made me much relaxed and my worries also reduced a lot. Thank you for the group work and thank you for Mr. Yip's assistance and guidance during the last six months.

IN153: Thank you for your participation in the interview, and of course, the MSG. I hope you and your daughter can live more happily and the illness will be recovered soon. Please be remembered that MARY should continue the follow-up and treatment, and MUM would continue the group participation for more mutual support and assistance. Health professionals are always ready for help if needed. All the best. That's the end of this interview if you don't have any questions.

MUM154: No question. Thank you. Bye.

End